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# EMPIRICAL BIOETHICS: THEORETICAL AND PRACTICAL PERSPECTIVES

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# Preface

This book was borne out of a mixture of excitement and frustration. Excitement because of our engagement with a developing field, 'empirical bioethics', which promises a great deal; and frustration because the emerging field threatens to be so multifarious and vague that making sense of it is a challenge for even the most seasoned researcher.

The premise that underpins empirical bioethics, however, is simple, and this book is largely accepting of that premise: a bioethics that is dominated by theoretical philosophical approaches is ill-suited to the job of engaging with, and prescribing about, complex ethical dilemmas. Rather these dilemmas require solutions that can be applied and defended in practice, rather than in the pages of an academic journal. A theoretical approach to bioethics provides a perspective that focusses on argument and theoretical consistency – but an approach to ethics that focuses wholly on argument and consistency risks ignoring the human element and sanitising what is, essentially, a very messy, social and human phenomenon. Good applied ethics must, accordingly, be attendant to the realities of moral life *as it is practised*, not (merely) as it is theorised about, because good applied ethics must have real world purchase; that is, it must be resonant with moral actors in the world, not just those in the academy.

There is certainly something compelling about the idea of real world purchase, but precisely what is meant by having 'real world purchase' remains moot. For us, and for the purposes of this book, we understand it as research that seeks, through engaging with empirical research, to meet one or more of the following three conditions:

## The veridical condition

*The research process attempts to ensure that the ethical issue being researched is genuine and authentic; framed in terms of the way it is experienced and negotiated in practice by moral actors, rather than constructed in abstract by a moral theorist.*

## The realist condition

*The research process attempts to ensure that the analysis is attendant to the circumstances in which moral actors find themselves, and pays due consideration to factors that may constrain or limit the actions or choices available to actors.*

## The pragmatic condition

*The research process attempts to generate conclusions/solutions to normative problems that are sufficiently respectful to, and engage sufficiently seriously with, the concerns and issues of relevant stakeholders, such that it is capable of being accepted and implemented.*

There are myriad ways in which these conditions may be met - which may be more or less successful - and arguably not all of them will necessarily involve first-hand direct engagement with empirical research. The strategy, however, that proponents of empirical bioethics have used has been to attempt to combine disciplines, or elements of disciplines, to produce methodologies for ethical inquiry that allow some kind of integration of normative and empirical research. Precisely what form that 'integration' takes can vary substantially and is down to the individual researcher to explicate, but broadly speaking we take it to mean a process in which the empirical and the normative are not seen as distinct and separate areas of inquiry (with the conclusions of one area merely 'imported' for use in the other area), but as mutually informing and, to some extent, symbiotic.

This focus on integration is significant, because it demarcates our account of empirical bioethics from other research strategies that are commonly included under this term. We take it that there are a number of other ways in which empirical research can be put to work in bioethics that do not meet the three conditions articulated here. The empirical identification of ethical issues in practice, the empirical substantiation of practical moral arguments, and the empirical evaluation of the implementation of ethical arguments/interventions into practice are commonly included in 'broader church' typologies of

empirical ethics. These empirical research designs raise their own problems and uncertainties, though they all differ from empirical bioethics as we are framing it because they are orientated towards meeting empirical objectives; they do not set out (at least explicitly) with the aim of generating solutions or conclusions to normative questions. Whilst we do not focus on these research activities in this book, our silence on them is not to discount their importance; either as studies that are equally relevant to developing our understanding of ethics in practice, or as activities that are potentially complementary to the empirical ethics research practices that are the focus of this book.

The enterprise of developing and articulating methodologies that explicate the process of integration in empirical bioethics research has been a major focus of the literature to date, and a recent systematic review of integrative empirical bioethics methodologies found 32 distinct approaches. This certainly shows that the field is active and developing, but we would take this opportunity to sound a warning; a warning that we hope permeates this volume, but which may seem like a counter-intuitive way to preface a book that is ostensibly concerned with methodology.

There is a real danger that such an overt focus on developing methodologies will lead the field to focus on *process* rather than *practice*; where a discrete piece of research is evaluated according to the extent that it follows the process set out in a prescribed methodology rather than evaluated on its own merits given its specific aims and objectives. Following the prescriptions of a tried and tested methodology is by no means a bad thing, but our concern is that there is a risk of methodological proceduralism, in which unreflectively following the steps set out, and describing them effectively and articulately might, at best, replace serious reflection on methodological choices or, at worst, hide a multitude of sins.

Accordingly we have sought, in this book, to bring together perspectives from researchers actively working in this field, who are both theorising about methodologies in empirical bioethics and conducting research that uses those methodologies. We have encouraged all our contributors, particularly those articulating methodologies, to say something new, clarify their positions and deal with criticism that has been previously levelled at their approach. Above all, every chapter in this book encourages the reader to think carefully about methodological choices, and consider the implications of epistemology and theoretical perspectives for their research.

This book is, then, is broadly anti-proceduralist. Our aim is to present a source book, not a text book: one that clearly articulates the key challenges in the field and provides accounts of methodologies that have been tried and tested, and in doing so provide the reader with material to take away, to reflect on, and to use to develop their own thinking. It is designed to present examples of how to think through the various challenges that empirical bioethics research presents and to stimulate thought – not to provide answers.

The book has been arranged into two broad sections, Section 1 comprising chapters about theoretical issues, and Section 2 comprising chapters outlining specific ways of doing empirical bioethics and other more practical concerns. This distinction is somewhat artificial and reflects differences in emphasis rather than anything more clear-cut. It is a product of the need to find a way to structure the book and is not a statement about the order in which questions ought to be approached, or which perspectives ought to be prioritised. In fact, as editors of this volume, our position is that the theoretical and practical considerations outlined herein cannot be separated. This is very much part of the excitement and challenge of the field: to find ways of approaching substantive moral questions which matter to practical actors, whilst taking seriously both the demands for rigour that properly attach to different forms of academic research and the theoretical and philosophical debates that inform these demands. We hope this book will help other researchers engage with, and confront, this challenge.

Jonathan Ives  
Alan Cribb  
Michael Dunn

# Section 1:

## Theoretical perspectives

# Theoretical perspectives: An introduction

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Research, in general, is complex. When we first come across it we may assume that it is a simple process, in which we make observations about the world and record our conclusions based on those observations. We later learn that this kind of simple research can only answer certain kinds of questions. As our questions become more complex, we learn that it is important to think about the lenses or theories through which we observe the world; that there are different approaches to observation and that observation alone may not be enough. For example, different kinds of experimental design are sometimes needed, where variables are controlled and hypotheses tested. We also learn that some kinds of questions cannot be answered by observing the world or carrying out experiments; some questions can only be answered by thinking them through and reasoning about them. We might then learn that there is a fundamental disagreement about how we can come to know anything at all, with one school of thought asserting that knowledge can be acquired through observation of the world (empiricism) and the other asserting that knowledge can be acquired through reasoning (rationalism). In the process, we will start to realise that the way we believe knowledge can be obtained, and the way we go about trying to acquire knowledge, is very greatly influenced by various assumptions and beliefs we hold about the world and the nature of knowledge. Assumptions and beliefs that we will all have, but of which we might not always be aware, make explicit, or be able to justify. These assumptions and beliefs about the world and how we can obtain knowledge form an epistemology (or 'theory of knowledge'); and when epistemology is used thoughtfully to inform and justify the use of a particular research method (or set of research methods), we have a research methodology – that is, a process for obtaining knowledge about the world, using various methods, which are made coherent by an underpinning philosophy that explains how we can move from a state of not knowing to knowing, and allows us to provide a justification for that state of knowing.

Research, then, *is* complex, and empirical bioethics is a candidate for being one of the most theoretically complex forms. This complexity is a result of its attempt to integrate two very different kinds of inquiry – normative and empirical – which have traditionally been seen as separate and, to some extent, incompatible. This, taken on its own does not, however, really explain very much. Two things traditionally being viewed as separate and incompatible does not mean that their combination is necessarily complex or problematic (just ask any five year old who's experimenting in the kitchen). The complexity of the attempt to combine normative and empirical research can, rather, be understood in terms of two distinct problems: one theoretical and one, for want of a better word, territorial.

The first problem that arises out of trying to combine these two very different forms of research activity is that of harmonising the epistemologies (and associated theoretical frameworks) that undergird their research methods, and of developing and using methods in ways that are consistent with those epistemologies. The second is that even if epistemological harmonisation is possible it will tend to result in the adoption of new or novel blended perspectives that do not fit neatly within disciplinary boundaries; thus requiring researchers to step outside of disciplinary silos into a new world of transdisciplinarity. We look at each of these problems in turn, before outlining how this section of the book attempts to shed light on them.

## **The problem of harmonising epistemologies and theoretical frameworks**

Any attempt to obtain moral knowledge – that is, to conduct research that aims to answer questions about what we ought to do, what we ought to think, or how we ought to act – is no different to any other attempt to obtain knowledge, insofar as even asking the question makes certain assumptions. When we ask a normative question – one that asks how we *ought* to act – we make at least three assumptions:

- i) We assume that the question makes sense (i.e. that it is meaningful to ask such a question);
- ii) We make an assumption about what an answer might look like (so that we will know it when we see it); and
- iii) We make an assumption about the way such an answer can be justified (so that we know whether or not we ought to accept it).

Different philosophical traditions and schools of thought will make different assumptions and assertions about all of these points, and so part of the process of conducting research to obtain knowledge about how we ought to act is being conscious of which school of philosophical thought (and specifically, which moral epistemology) one is aligned with.

Similarly, any attempt to obtain empirical knowledge – that is to conduct research that aims to answer descriptive questions about what we actually do, what we actually think, or how we actually act – makes a series of assumptions about the social world and how we obtain understandings of it. We make assumption about the underlying realities of the social world and whether or not it is possible to understand it independently of the research process; and we make assumptions about how we can, (and should) interpret and understand cultures and practices. Different social scientific schools of thought will make different assumptions and assertions about all of these points, and so part of the process of doing research to obtain knowledge about how people do act/think/experience is being conscious of which empirical epistemology one is aligned with.

As outlined in the preface, the unique quality of empirical bioethics, as we are defining it here, is that it aims to be integrative: to combine normative and empirical research practices, and not simply to conduct separate empirical and normative studies in parallel. As such it has to take seriously, and combine, both normative and empirical epistemologies; and a great deal of intellectual legwork is required in order to be able to tell a coherent theoretical story about how one can combine the empirical and the normative, and how one can obtain both empirically informed and useful normative conclusions that are appropriately justified.

The most significant challenge of this kind that empirical bioethics faces, if the current and recent literature is anything to go by, is to explain how we can draw conclusions about the way the world should be (making 'ought' claims) in a way that has been meaningfully informed by observation and understanding about the way the world currently is. The challenge, broadly conceived, can be narrated as follows:

*Ethics is fundamentally a normative enterprise, in the sense that it wants to be able to make statements about how people ought to act, regardless of how they actually do act.*

*Recent critiques of bioethics, however, have challenged the traditional philosophical approach to doing bioethics research, claiming that philosophical bioethics is too abstract and too disconnected from people's lived moral experiences to be capable of making 'ought' claims about the world (Hedgecoe, 2004; Hoffmaster, 2001; De Vries et al, 2006; Borry et al, 2005; Ives 2008). In order to be capable of making 'ought' claims that can be taken seriously, bioethics needs to pay attention to context and to what people actually do and think (and why); and the way to do this is to pay close attention to empirical (typically, social scientific) research.*

*Philosophical Bioethics might respond, and claim that good applied ethics must, and has always, has paid attention to the empirical world and used empirical research (Herrera, 2008), and so the challenge to philosophical bioethics is nothing but a straw man.*

*But, says the critique, that is exactly the point. Philosophical bioethics uses empirical research; the same way a queen uses a handmaiden (Haimes, 2002). When it wants something, it asks for it, and then it sends it away. Paying attention to the empirical world is more than simply using facts to support argument - what Ashcroft (2003) has called 'completing the hypothetical imperative', where a philosophical argument requires certain facts to be established, and so appeals to empirical research to establish the facts. Paying attention to the empirical world means learning from it, and using the empirical to inform our thinking about which values are and should be important. In other*



*words, the empirical ought not to be a handmaiden to the normative (philosophical) monarch, it should be a partner. It should not simply be consulted when a philosophical argument requires a fact, but should be integrated into the process of working out what our values ought to be.*

This basic idea presents us with a problem, because much contemporary analytic philosophy contends that ethical and factual claims are fundamentally distinct; the former being normative and the latter being descriptive. For many people, as McMillan & Hope note, “the normativity of ethics rules out the possibility of it’s being done in a factual or empirical way” (2008;14), and this is explained by appealing to various philosophical tropes, broadly expressed as follows:

- 1) One cannot derive an ‘ought’ claim from an ‘is’ claim. Any ‘is’ claim is simply descriptive of a contingent state of affairs; additional reasoning (in the form of a bridging value premise) is required in order to establish that what ‘is’ also ‘ought’ to be. Given that, empirical bioethics is deeply problematic, because it requires us to make a leap from our understanding of what ‘is’ (described by empirical research) to making claims about what ought to be; and no move from ‘is’ to ‘ought’ can be justified.
- 2) Ethics is concerned with ‘values’ and empirical research is concerned with ‘facts’. Facts are independent of values; they are simply descriptive and value free. Moral values, on the other hand, are not dependent on facts, and neither can they be reduced to facts. Moore’s Open question argument attempts to show this, by pointing out that one can attempt to reduce a value to a fact (such as ‘morally good’ can be reduced to ‘pleasurable’), but one can always ask meaningfully ‘is pleasure good?’. The fact that that question is meaningful, and can always be asked, shows us that values cannot be understood simply in terms of natural properties.

A significant challenge, then, for proponents of empirical bioethics, is how to account for the relationship between empirical ‘is’ claims and normative ‘ought’ claims in a way that does not conflate facts and values and does not make an ‘ought’ directly derivative from an ‘is’. As Ives and Draper (2009) have argued, “no sane defender of empirical bioethics is likely to suggest that we unreflectively use empirical data to determine what we morally ought to do” (pp254). Rather, they contend, that:

[t]he real challenge is to determine what role empirical data can play... and how it can be integrated into normative ethical reasoning in a way that respects the sound empirical point that facts and values are not distinct in practice, but that also does not fall foul of the is/ought problem as defined in philosophical terms (pp254).

However, to consider this challenge as fundamental or insurmountable makes the mistake of assuming that all of ‘philosophy’ is united in the way that it understands the relationship between fact and value. As McMillan (2016) notes, in his chapter from this volume, the empiricist epistemology that asserts the distinction between fact and value is not universally accepted, and:

we have good reason for being cautious about basing objections to empirical ethics upon 18th century British Empiricism, which is a radical and controversial epistemology. (pp)

Whilst few might go so far as to support Hedgcock’s (2004) (dismissive) claim that the is/ought problem or fact/value distinction are ‘figments of the philosophical imagination’, others might point to different philosophical traditions, and different ways of explaining the interaction between is/ought and between fact/value. Once one takes a broader view, and considers what different philosophical traditions might have to offer, one can begin to see how and why the notion of integrating the empirical and normative cannot be dismissed out of hand. For example; Haimes and Williams (2007) have proposed a methodology drawing on a notion of ethical particularism and Aristotelian phronesis, which supports an understanding of ethics as an activity that develops from context. Parker (2009) proposes ‘Teleological Expressivism’ - a position that endorses a form of ethical naturalism and explains how empirical data can inform the making of normative judgements by explaining the role of emotion in practical rationality. Ives (2015) proposes ‘quasi-moral foundationalism’ – a position that draws on philosophical pragmatism and moderate pragmatic naturalism to describe fact/value entanglement, and justify an approach to empirical bioethics based on a particular understanding of the function of bioethics and the requirement to compromise. In this volume, Landweer et al (2016)

draw on Gadamer's hermeneutic philosophy to explain how the varied experiences and perspectives of stakeholders are integral to the development of normative solutions, through a process of dialogue and interpretation. What is important in all of these approaches is that they have taken pains to acknowledge and engage with the problem of is/ought and fact/value, but have attempted to provide an internally coherent epistemology and theoretical framework to explain the relationship between the empirical and the normative - one that does not assume 18th century British Empiricism is authoritative on the issue.

It is, however, important to consider that although much of the focus of the empirical bioethics literature has been on how to manage the is/ought problem in a way that allows us to make justifiable normative claims, there are others who are thoughtfully sceptical about this ambition. Some commentators, working in a broadly Weberian tradition (e.g. Hamersley, 2000), urge extreme caution in attempts to integrate empirical and normative forms of scholarship, on the grounds that attempting anything other than 'bracketing out' normative considerations is liable to undermine the possibility of empirical rigour. Even so, Hamersley's point about the need to aim for empirical research that is as 'value neutral' as possible does not speak against the project of empirical bioethics, nor the project of developing empirically informed normative judgements. As Gewirtz and Cribb (2006) note:

[Hamersley] is against any assumption on the part of researchers that they are better qualified than those they are studying to make the everyday moral decisions that the people they are studying have to make. He is also opposed to the tendency for researchers to recommend courses of action that are impractical or that risk making matters worse rather than better. Above all, Hamersley is opposed to researchers prescribing courses of action as if they follow from their research findings rather than from their prior political or ethical beliefs. (pp145)

These are concerns that many proponents of EB will share and, as attested to in this volume, attempt to address through their methodologies. Hamersley, however, is also concerned that social researchers ought to make every effort to separate their own values from their search for facts, arguing that:

[t]he closer we can approximate to [value-neutrality], the less the danger of our political or practical values biasing our results (Hamersley, 2000;33).

Whilst the question of whether anything approaching value-neutral empirical research is possible is moot, it is certainly the case that some contributions to the EB literature seems to assume it can be done, and is unproblematic (e.g. Kon, 2009), whereas others are explicitly critical of this assumption (e.g. Dunn & Ives, 2009). What is certain is that engaging in empirical bioethics requires one not only to consider the relationship between facts and values in the sense of how one make empirically informed normative judgements, but also the relationship between facts and values in the empirical research process itself.

Another way of understanding this kind of concern is that in focussing all our attention on how to address the normative, we may become less attentive to the need to fully address the empirical, and ensure that our empirical data collection is rigorous. Practitioners of empirical bioethics have certainly been accused of being insufficiently attentive to empirical rigour, with concerns that bioethics treats empirical data collection methods as a simplistic and philosophically unproblematic set of tools (Dunn & Ives, 2010), or simply that empirical bioethics has failed to import the standards of empirical research, both in conduct and critical appraisal (Hurst, 2010; Strech, 2010; Provoost, 2015), leading to poor quality work. As Singh (2016) argues in her chapter in this volume, failure to be attentive to the quality of the empirical work undertaken risks the entire enterprise of empirical bioethics.

### **The problem of harmonising disciplines**

When we introduced this problem above we described it as 'territorial' (for want of a better word), but this perhaps does the problem a dis-service. Arguably, there is a territorial angle to the difficulties faced by working across disciplines, and the problems empirical bioethics has faced in this regard have been described by some as a territorial dispute, with disciplines vying for dominance over the (battle)field (for example: Molewijk & Frith, 2009; Ives, 2008). Indeed, the analogy of the social

scientist as handmaiden to the philosophical monarch in bioethics, mentioned above (Haimes, 2002), is one that is fundamentally about disciplinary power and control over the normative and what counts as good normative justification. In using that analogy, one makes a point about where the power lies in bioethics, and might, for example, be suggesting that bioethics should not be dominated by philosophy and (Western analytic) philosophical perspectives on how normative claims can be made and justified. Where the 'power' in bioethics lies is important, and arguably has implications for funding, publication, and ultimately the structure of research and teaching institutions (see also Frith & Draper's chapter, this volume). There is more to it, however, than disciplinary tub-thumping and argument over who exercises control over an academic field. This can be managed; we can all play nicely together if we want to (and an excellent example of this can be found in Farsides & Williams' account of their longstanding interdisciplinary collaborations, in this volume).

The more substantive challenge around disciplinary harmonisation is finding sufficient common ground, and a sufficiently common language, to begin to build something that goes beyond traditional disciplinary boundaries and stands alone, not beholden to a dominant 'parent' discipline. This requires us to go beyond merely harmonising theoretical perspectives so that we have a coherent epistemology; it requires us to understand and take seriously the challenges and demands of rigour that other disciplines bring to the table; and not dismiss an idea because 'that's not the way we do things', but to genuinely suspend disciplinary assumptions – what DeWachter (1982) refers to as 'epoche' – and this is no mean feat. It requires a reflexive and creative approach, and a genuine thirst for new ways of discovery.

### **Theoretical and territorial considerations**

In this section, we present chapters that explore some of these theoretical and territorial issues. They give the novice reader grounding in some of the key issues and debates, but they also offer the more experienced researcher a positive account of, and argument for, how we might deal with them.

In the first chapter, John McMillan explores the complex concept of 'normativity' through discussion of the fact-value distinction, which is so central to many of the debates in empirical bioethics, and offers insight into how taking a particular stance on the fact/value distinction can impact on how one might approach empirical bioethics research. It also explores how different disciplinary perspectives might understand, and use, the concept of 'normativity' in different ways. McMillan unpicks and delineates three distinctive meta-ethical issues: the fact/value distinction; the is/ought problem; and the naturalistic fallacy, and explores the implications of each for empirical bioethics. McMillan's key task is to challenge the standard philosophical rebuke to empirical bioethics that facts and values are entirely distinct. Rather, he argues, that:

[t]he traditional empiricist version where fact and value are dichotomous is arguably untenable, and yet has shaped approaches to empirical bioethics..., and is sometimes used to argue that the whole project of empirical bioethics is untenable. Further reflection upon the different kinds of value sheds light on how it is that different approaches to bioethics can be normative, but in different ways. (pp??)

The second chapter, from Mark Sheehan, details the 'problem' of moral relativism: what its impact is for empirical bioethics, and how empirical bioethics might attempt to manage it. Perhaps unsurprisingly, given the centrality of this meta-ethical question to debates in empirical bioethics, this chapter links back to the discussion of fact/value in McMillan's preceding chapter, and foregrounds many of the issues that are discussed in detail in proceeding chapters, including the notion of expertise, the status of robust empirical data, and questions about authority and legitimacy in making moral judgements. Importantly, Sheehan takes the key issues in the philosophical debate around moral relativism, and transposes them into the debate about empirical bioethics methodology, illustrating forcefully their relevance and significance. The chapter ends with an articulation of a 'moderate objectivist' position, attributed to David Wiggins, which, argues Sheehan, is a meta-ethical position that:

represents a very serious attempt to acknowledge the ethical significance of context, practice and perspective, but at the same time offers a robust account of the

methodology of ethical and conceptual argument which can claim authority in the face of the relativist's scepticism. (pp??).

This chapter, then, presents both an account of the challenge that moral relativism might pose to empirical bioethics, but also provides an accessible philosophical account of ethics that might provide a theoretical grounding for various forms of empirical bioethics methodology.

Kyle Edwards & Zuzana Deans provide, in chapter three, an exploration of the issues of professionalism, expertise and authority, which are central to empirical bioethics, but rarely examined in relation to it. Edwards & Deans argue that one of the central driving forces behind empirical bioethics is the claim that it seeks to develop 'a way of doing bioethics that gives it a legitimate place at the policy table', premised on the notion that empirical bioethics allows us to conduct bioethics research that is better grounded in the real world than philosophical bioethics. They approach the question, however, in reverse, by first exploring what legitimises the place of ethicist *per se* at the policy table, and exploring what authority, expertise and legitimacy they have. Based on their answer to that question Edwards & Deans then consider how the way that we justify and legitimise the role of an ethicist in policy making must impact on the way that the ethicists themselves develop and represents their own ethical position. There is, in essence, a *drawing down* of legitimacy, whereby the ethicist ought to be cognisant of choosing a methodology for developing and justifying a position on a normative issue that is compatible with the political justification for their presence and role in a public policy forum.

Chapter four, by Ilna Singh, provides something of a bridge, which begins to blend important considerations about theoretical perspectives in empirical research with comments about disciplinary harmony and rigour. The central message coming out of Singh's chapter is that empirical bioethics needs to take seriously, and engage with, the substantial theoretical challenges involved in discovering empirical facts – what we might see as a rejection of the simplistic 'tool kit' approaches to empirical data gathering that some advocates of empirical bioethics seem to accept (see above).

Singh's chapter does many things. It challenges the use of the term 'empirical data' to refer to an homogenous and interchangeable category, and encourages the empirical bioethics researcher to be more sophisticated in their understanding of what different kinds of data can offer and to think carefully about what kind of data is best suited to an integrative empirical bioethics analysis.

It highlights the vital importance of being attentive to the framing of an empirical question within empirical bioethics research, emphasising that the way a question is framed has an impact on the empirical methods and methodology that can be used to answer it; the empirical method and methodology that are used then has an impact on what answer we get and how those answers are understood; and in turn the answers we get and the way they are understood have an impact on how they are and can be integrated with a normative analysis. Similarly, if we begin with a theoretical perspective about ethics, this will impact on what empirical methodologies we are attracted to and use, which will in turn affect the kind of empirical data we collect. The central argument is that empirical bioethics research must be viewed as an holistic enterprise – where inattention to the coherency of empirical and normative components creates significant problems.

Finally, it draws our attention to the dangers of developing methodologies in empirical bioethics that replicate (or create) hierarchies of approaches, where different kinds of analysis are conducted by separate groups (or people) and the findings passed onto the next as a part of a production line. This is a point that address the territorial issue more than the theoretical one, but it arises directly out of methodological reflection. "The integrity of the empirical data", argues Singh, "is lost when it functions as a means to an end" (pp??).

The fifth chapter in this section sees Richard Huxtable articulating the relationship between bioethics and law, using an extended metaphor of 'friends, foes and flatmates'. In particular, Huxtable considers how law, as a fundamentally practical and empirically founded enterprise that "must have purchase in the real world", has lessons for bioethics, particularly empirical bioethics, as it tries to develop into a field of research that has similar real world purchase. More broadly, the chapter is an exploration, perhaps more accurately an exposition, of how conversations between disciplinary perspectives, which aim to genuinely understand and learn, can be productive and useful. The conclusion Huxtable draws, that "[we] should... continue to configure the relationship between law

and bioethics, moving it on from its “haphazard” beginnings” (pp??) rings true more generally. Empirical bioethics must continue to configure the relationships between all of the disciplines that contribute to it, so that it can move beyond a haphazard conglomeration of ideas competing for dominance, and into a more settled, happy, but almost certainly unconventional, marriage.

The sixth and final chapter in this section, from Cribb & Owens, follows on from Huxtable’s specific examination of the relationship between law and bioethics, and considers more generally the value of diversity in empirical bioethics. It does this by first setting up a stereotypical conflict between the ‘Philosopher’ and the ‘Social Scientist’ that attests to the incommensurability of the two approaches. It then explores the heterogeneity of approaches within those disciplines themselves, and in doing so argues that the general criticisms that a philosopher may have of a social scientific approach applies to many philosophers as well, and vice versa. The argument is that the points of contestation within empirical bioethics are not necessarily fought along disciplinary lines – to assume they are is to assume that disciplines have a homogeneity that they simply do not have and encourages a disciplinary tribalism of a very unhelpful kind. Rather, what is more important is asking about the aims of the research – which Cribb and Owens characterise using the axes of engineering or enlightenment aims, and descriptive and normative aims. They problematise the notion of one’s research aims being determined by one’s discipline, and the overriding point to take away from this is that embracing and recognising the diversity of aims and methods within disciplinary perspectives, as well as within bioethics, may be the key to effective transdisciplinary work in empirical bioethics.

## **Final words**

This first section of the book ends with an entreaty to embrace diversity, but this appeal must be accompanied by a health warning. As Cribb & Owens note, embracing diversity does not mean that ‘anything goes’. If there is a core message of this book, it is that all methodological decisions, underpinned as they must be with a sound and coherent theoretical framework, must be well reasoned and justified. The entreaty to embrace diversity means that empirical bioethics needs to be open to different ways of thinking and be creative in its approach, but it must also be rigorous. We end with a quotation from a recent systematic review on methods in empirical bioethics, which sets the scene well for the chapters to come:

For now, our view is that everyone working in this field must live with a great deal of uncertainty, and will have to work hard to explain what they are doing and why it ought to be taken seriously. If we are trying to do a new kind of ethics, using new kinds of methodologies, then we should be put under pressure to justify and articulate that new approach clearly. At this stage in the development of empirical bioethics, that means engaging explicitly and meaningfully with questions concerning the kinds of moral claim that empirical bioethicists want to be able to make, about normative justification and the methodological process, and about the coherence of these different components of their work. So long as this is done, the evident heterogeneity doesn’t matter, and should in fact be welcomed. (Davies et al, 2015;12).

## References

- Ashcroft R. 2003. Constructing Empirical Bioethics: Foucauldian Reflections on the Empirical Turn in Bioethics Research. *Health Care Analysis*. 11(1): 3–13
- Borry P, Schotsmans P, Dierickx K. 2005. The Birth of the Empirical Turn in Bioethics. *Bioethics*. 19(1): 49–71
- Braddock C. 2010. Empirical methods in bioethics: A cautionary tale. *Annals of Internal Medicine* 152(6):396-397
- Davies R, Ives J, Dunn M. 2015. A Systematic Review of Empirical Bioethics Methodologies. *BMC Medical Ethics*, 16.
- DeWachter M. 1982. Interdisciplinary Bioethics: But where do we start? A reflection on Epoche as Method. *Journal of Medicine and Philosophy*. 7: 275–287, 286.
- Dunn, M., Ives, J. 2009. Methodology and epistemology in bioethics research: A constructive/ist commentary. *American Journal of Bioethics*. 9(6-7):93-95
- Frith L, Draper H. 2016. Publishing research in empirical ethics: Quality, disciplines and expertise. **This Volume.**
- Gewirtz S, Cribb A. 2006. What to do about values in social research: the case for ethical reflexivity in the sociology of education. *British Journal of Sociology of Education*. 27(2):141-155
- Haimes E. 2002. What Can Sociology Contribute to the Study of Ethics? Theoretical, Empirical and Substantive Considerations. *Bioethics*. 16(2)
- Haimes, E. Williams, R. 2007. Sociology, Ethics and the priority of the particular: learning from a case study of genetic deliberations. *British Journal of Sociology*. 58(3):457-476.
- Hammersley, M. 2000. Taking sides in social research: essays on partisanship and bias. London: Routledge.
- Hedgecoe A. 2004. Critical Bioethics: Beyond the Social Science Critique. *Bioethics*. 18(2): 120–143
- Herrera C. 2008. Is it Time for Bioethics to Go Empirical? *Bioethics*. 22(3): 137–146. 5
- Hoffmaster B. 2001. Introduction. In *Bioethics in Social Context*. B. Hoffmaster, ed. Philadelphia: Temple University Press: 2.
- Hurst, S. 2010. What 'Empirical Turn' in Bioethics? *Bioethics* 24(8):439-444
- Ives J. 2013. A method of reflexive balancing in a pragmatic, interdisciplinary and reflexive bioethics. *Bioethics*, 28(6):302-312
- Ives J, Draper H. 2009. Appropriate methods for empirical bioethics: it's all relative. *Bioethics*, 23(4):249-258.
- Ives, J. 2008. 'Encounters with Experience: Empirical Bioethics and the Future', *Health Care Analysis*. 16:1-6
- Kon A. 2009. The role of empirical research in bioethics. *American Journal of Bioethics*, 9(6-7):59-65.
- Landeweer E, Molewijk B, Widdershoven G. 2016. Moral improvement through interactive research: An example of dialogical empirical ethics. **This volume**

McMillan J. Hope T. 2008. The possibility of empirical psychiatric ethics. From Widdershoven G. McMillan J. Hope T. van der Scheer L. Empirical Ethics in Psychiatry. Oxford University Press: Oxford.

McMillan J. 2016. Empirical Bioethics and the fact/value distinction. [This volume.](#)

Molewijk B, Frith L. 2009. Empirical Ethics: Who is the Don Quixote? Bioethics, 23(4), 2-4.

Parker M. 2009. Two concepts of empirical ethics. Bioethics. 24(4):202-213

Provoost, V. 2016. Secondary use of empirical research data in medical ethics papers on gamete donation: forms of use and pitfalls. Monash Bioethics Review. 33(1):64-77

Singh I. 2016. Evidence, Epistemology and Empirical Bioethics. [This volume](#)

Strech D. 2010. How factual do we want the facts? Criteria for a critical appraisal of empirical research for use in ethics. Journal of Medical Ethics, 36:222-225

deVries R. Turner L. Orfali K. Bosk C. 2006. Social Science and Bioethics: The Way Forward. Sociology of health and Illness. 28(6): 665–677;



# Empirical Bioethics and the fact/value distinction

John McMillan

## Introduction

At first blush, there seems something compelling about the idea that there is a profound difference between matters of fact and values. Facts are the proper domain of science and seem to imply objectivity and being truth apt. Values would seem, on the other hand, to be inherently subjective, revisable and not truth apt. The idea that ethics, which is a subject that deals primarily with questions of value, could be empirical grates on some because it sounds as if more epistemic weight is being given to ethics than it can bear. This is not to deny that we might find out something about what people in fact value via empirical methods; rather, more that it is a mistake to think that any kind of empirical investigation can further our understanding of what we should value or do.

The philosophical underpinnings of that intuition, and how empirical approaches to ethics might respond to it, have been given significant attention over the last twenty years and there appears to be an acceptance, albeit grudging, among those who view bioethics via a philosophical lens, that there is a role for empirical approaches to ethics.

Empirical ethics has become accepted to the extent that the American Journal of Bioethics, which has the highest impact factor of any ethics journal, has now started a sister journal publishing empirical ethics research; and there have been a number of articles, special issues and books published arguing for empirical ethics.

Nonetheless, there are empirical approaches to ethics that are heavily influenced by the traditional philosophical fact/value distinction. Fulford's (2004) 'values based medicine' is the most prominent example, where a sharp dichotomy between facts and values, and scepticism about the epistemic status of values, shape the theory. Unpacking where such views have gone astray involves revisiting the assumptions that underpin the fact value distinction. I will show, in this chapter, why we should not grant these assumptions and consider what the implications of this are for how we should view empirical bioethics.

Thinking more carefully about the different kinds of value (or normativity) that make a sharp dichotomy between fact and value untenable can also explain how both sociological and philosophical approaches to bioethics are normative, but in distinct ways. 'Sociological epistemic values' are the epistemic norms of medical sociology and they encourage a critical perspective upon issues within bioethics. Such values explain not only how medical sociology is normative, but also why it is that empirical bioethics offers something new and distinct from classic medical sociology.

## The fact value distinction

It is worth noting, as Mackie (1977) does, that philosophy has not always taken values to imply a lack of objectivity: for Plato the just and the beautiful were formal, objective and appropriately considered within the realm of 'knowledge.' Nonetheless, since Hume and the other British Empiricists, there has been a commonly held conviction that values are mere sentiment and need to put to one side when our aim is the pursuit of knowledge. While this is a scepticism that is true of values more generally, it is ethics where that challenge has had greatest bite.

One of the most quoted passages in Hume, and the one that many will identify with the fact value distinction, is from the Treatise where he describes the logical problem of deriving a normative conclusion from purely factual premises.

In every system of morality, which I have hitherto met with, I have always remarked, that the author proceeds for some time in the ordinary ways of reasoning, and establishes the



being of a God, or makes observations concerning human affairs; when all of a sudden I am surprised to find, that instead of the usual copulations of propositions, is, and is not, I meet with no proposition that is not connected with an ought, or an ought not. This change is imperceptible; but is however, of the last consequence. For as this ought, or ought not, expresses some new relation or affirmation... (Hume, 1956: 177-178)

There are different ways of interpreting this passage. Putnam (2002) and many others have taken it to imply a radical scepticism about the impossibility of ever grounding normative claims. But Hume can also be interpreted as merely making a logical point about the tendency to move quickly from a discussion of how things are, be that human nature or human affairs, to a claim about how things should be (Pigden, 1989). If that's all that the fact/value distinction amounts to then this poses no great challenge to empirical approaches to ethics, all that needs to happen is that those who are engaged in empirical bioethics need to be mindful about the ethical premises that they're using to derive a normative conclusion. There will be cases within bioethics where normative claims are drawn too hastily from an empirical study, and where a normative premise should have first been stated.

For example, a qualitative study about neo-natal decision making might observe that parents value being fully informed about a changing prognosis and taking an active role in decision making about their very unwell child making (for an example of such a study see McHaffie et al, 2001). If the authors of such a study concluded from this alone that parents should always be informed and take an active role in decision-making they would be committing a logical fallacy of this kind. It does not follow from the fact that a group of people value something and have a preference about it that what they want is what should happen. Those interpreting such a study need to argue this out and add normative premises such as 'parental autonomy is an important principle that implies we should give parents a greater right to decide' in order to make the normative conclusion follow. In such a case, that does not seem like anything more than a reminder to pay heed to the importance of checking that a deontic argument is valid. These are points that are worth bearing in mind for anyone seeking to combine empirical and normative investigation, and are explored by McMillan and Hope (2008) in 'The possibility of empirical psychiatric ethics'.

However, elsewhere in the Treatise it is clear that Hume is making a deeper point about the epistemology of value, and is developing a position that if true would create serious problems for scholarly inquiry into ethics and aesthetics. For Hume, all knowledge derives from the senses via sense impressions (for more on British Empiricism and how Hume fits within that tradition, see Mackie, 1980; Raphael, 1969). Simple ideas, from which all knowledge is built, are faint copies of sense impressions. So, for example, my idea of 'blueness' is a faint copy of the sense impression that I have when I look at the sky on a cloudless day.

Simple ideas can be associated with other ideas forming complex ideas, the stuff of which all knowledge is constructed. For example, I might form the idea of a 'sphere' from looking at a ball. That idea can be associated with my idea of 'blueness' and I am thereby able to perceive and have thoughts about a blue ball.

So far so good for a grounding of factual knowledge in the testimony of the senses; but values are not so easily given an empiricist grounding. As Paul Griffiths (1997) has observed, the fact/value distinction is drawn very sharply by Hume because of his arguments about the impossibility of grounding the passions. In the following passage, Hume argues for a form of non-cognitivism about values, which in this context means that values are not truth apt and are mere sentiment.

Where a passion is neither founded on false suppositions, nor chooses means insufficient for the end, the understanding can neither justify nor condemn it. It is not contrary to reason to prefer the destruction of the whole world to the scratching on my finger. It is not contrary to reason for me to choose my total ruin, to prevent the least uneasiness of an Indian, or person wholly unknown to me. (Hume, 1956:128)

For Hume, passions should be understood in an expansive sense so as to include emotions, values, aesthetic and moral judgements: in effect anything that motivates us to act or is normative. He is clear that there are cases where a passion is premised upon a false belief and in such cases a passion

could be contrary to reason. For example, if I am moved by the beauty of a Van Gogh painting because of the tragedy that was unfolding in his life at that time, but when the painting is in fact a modern work painted in the same style, my passion might be viewed as contrary to reason because it is premised upon a false belief about the nature of the painting. Likewise, if I desire and eat ice cream because I wish to eat only foods that will enable me to lose weight, that desire is contrary to reason in the sense that it is a means that is insufficient to the end of losing weight.

In the case of an ethical value, it too might be premised upon a false observation and thereby contrary to reason. For example, a passer-by might intervene if they see a woman distressed while being held by a man and say, 'let her go, it's wrong to treat someone like that.' But, if the man and woman were in fact engaged in performance art and this was a piece of street theatre, then they might break role and explain that in fact no one was harmed and it was mere pretence. Hume's point is that in both of these cases while there are factual errors that can lead the passions astray, the passions themselves cannot have a basis in matters of fact.

Passions themselves, except for the cases of factual error described above, cannot admit of truth or falsity, principally because of Hume's commitment to a particularly strict version of 18th century empiricism. For Hume, all knowledge derives from sense impressions and because we do not directly perceive the passions and they therefore cannot be built via the association of ideas, they cannot be matters of fact and therefore are not truth apt.

It's worth pausing to think about how radical Hume's proposal is and what it would mean for areas such as ethics and aesthetics. Some have taken it to imply that moral claims fail to constitute claims at all and are merely expressions of emotion, see Ayer's 'Language, Truth and Logic' (1946) for an example. It is also worth thinking about the other possibilities for grounding the passions that are being denied. Rationalists about ethics believe that normativity can be grounded in the structure of our rationality, as opposed to judgements about how the world is. That view is one with a rich history and is the backbone of Kant's theory, where normativity is derived from the nature of a good will. So, we have good reason for being cautious about basing objections to empirical ethics upon 18th century British Empiricism, which is a radical and controversial epistemology.

There is a connection between Hume's views about the passion's lack of rationality and G E Moore's claims about the naturalistic fallacy, but it is important to remember that they are distinct meta-ethical views. In Moore's own words, the naturalistic fallacy occurs:

When a man confuses two natural objects with one another, defining the one by the other, if for instance, he confuses himself, who is one natural object, with "pleased" or with "pleasure" which are others, then there is no reason to call the fallacy naturalistic. But if he confuses "good," which is not in the same sense a natural object, with any natural object whatever, then there is a reason for calling that a naturalistic fallacy; its being made with regard to "good" marks it as something quite specific, and this specific mistake deserves a name because it is so common. (Moore, 1903:s12)

Although these views have something in common and perhaps also a lineage, Moore's view is not Hume's. Where Hume was concerned about the logical problem of constructing an ethical argument from purely factual premises and the impossibility of finding sense impressions that ground the passions, Moore is more concerned with attempts to reduce claims about the passions, or in his terms 'non-natural' properties, to matters of fact or natural properties. Perhaps the most important example he discusses is attempting to define or reduce 'goodness' to 'pleasure.' According to Moore, defining the good in this way falls foul of the naturalistic fallacy and runs the risk of inviting an 'open question'. Whenever a property such as 'good' is equated with pleasure it is always possible to sensibly pose the question 'but is pleasure good?' The idea is that there is more to non-natural properties than can ever be captured by it being defined in natural terms; they are essentially irreducible.

Although Moore is, like Hume, an empiricist, they draw quite different epistemic implications from their similar view that 'the passions' or 'non-natural' properties are independent of the factual or natural. At least, in the early Hume, the independence of the passions from the factual implies that morality and aesthetics, insofar as they are scholarly areas of inquiry, appear to be founded upon some kind of

mistake. Moore, on the other hand, seems more driven to protect the importance of viewing the good or the beautiful in their own terms. Rather than implying irrationality, the irreducibility of non-natural properties preserves their status as things to which we should aspire. Just as Plato thought that perceiving the 'just' or the 'beautiful' involved apprehending something formal and therefore truth apt, Moore seemed to think the irreducibility of the non-natural did not mean they could not be perceived in the world and be truth apt. His point is, rather, that we should not mistake those perceptions for others that are of a natural kind.

The difference between Hume and Moore has some interesting applications for how we should conceptualize empirical ethics, but before turning to what might follow from a Moorean view, I will discuss the way in which Hume's assumptions have shaped one influential approach to empirical ethics.

### **Ten principles of values based medicine**

In 'Ten principles of values based medicine' (2004) Bill Fulford develops a method for discussing values in psychiatry that can be considered a form of empirical ethics. Values based medicine (VBM) is intended to act as the counterpoint to evidence based medicine (EBM). VBM is not, so the story goes, intended to supplant EBM; instead the idea is that because EBM involves the critical appraisal of evidence so as to reach rational determinations about matters of fact, it misses the importance of also having a way of making decisions about questions of value. So VBM is filling in part of the picture that is missed by EBM. We should consider VBM to be an example of empirical ethics because it has similar aims to EBM: to transform clinical practice by making decisions more structured and responsive to research informed evidence. VBM aims at providing a values base, similarly grounded in a method for generating claims about values, which can also be fed into clinical practice so as to ensure it is sensitive to values. The aims of both EBM and VBM are worthy, and mesh research activity with clinical practice. So VBM emphasises, as does EBM, the importance of particular kinds of research activity and should therefore be considered a form of empirical ethics. A second reason why VBM qualifies as empirical ethics is because it is being used as a methodology for producing accounts of what patients value (Petrova et al, 2006; Fulford, 2011).

In addition to supplementing EBM, it's also clear that Fulford thinks VBM is an antidote to ways of approaching bioethics that he finds lacking. He says that VBM is 'a skills based counterpart to the currently dominant quasi-legal form of clinical bioethics' (2004:205). He explains this point as follows:

Values based medicine, then, aims to resolve differences, not by consensus but by what I have called elsewhere "dissensus"... that is, by processes that support effective action through a balance of legitimately different value perspectives. It is worth looking at this notion of dissensus in a little more detail, since it is at the heart of the practice of VBM. Thus, in the quasi-legal model of bioethics, differences of values are resolved, in principle, by reference to a rule (embodied in a code or guideline and often supported by law), which has been settled in advance by consensus. Differences of interpretation may arise, of course, but these are settled, again in principle, by reference to a regulatory body with executive decision-making powers. (Fulford, 2004:216)

In the footnote to this claim Fulford mentions the United Kingdom's Human Fertilisation and Embryology and Authority (HFEA) by way of illustration, which does operate in a quasi-legal way, principally because it is a body given a mandate by an Act of Parliament. Even so, it seems unfair to the HFEA to criticise them for failing to acknowledge 'dissensus'. In fact, the HFEA have been criticised for giving too much weight to the views of the public, for example in its report on sex selection (Harris, 2005).

In any case there is a more substantial problem with Fulford's view because he appears to be providing a solution to a straw man problem. It's not obvious that anyone working in bioethics would describe their method as being one where disagreements about value are resolved by reference to a rule. What's much more common, and is illustrated particularly ably by Jonathan Glover in his chapter on the scope and limits of moral argument in 'Causing Death and Saving Lives' (1977), is that values

are tested for their scope, consistency and consequences in moral argument. It is hard to think of any example of a decent and published bioethical argument that reaches consensus between values via the adjudication of a pre-accepted rule.

The reason why it is vitally important in bioethics to argue carefully about the scope, consistency and consequences of values is because, contra Fulford, not all values are legitimate. He claims that 'human values are not, merely, different but legitimately different' (Fulford, 2004:215). An assumption behind this belief, and perhaps another reason for distinguishing VBM from bioethics, is that the view that serious inquiry into the nature of values, and attempts to ground values, are fundamentally mistaken. This becomes apparent in the endnote attached to this claim where he describes in more depth what he means by 'values'. He says

That our values are not only different but legitimately different follows analytically from the logical separation of fact and value (or, more exactly, of description and evaluation) insisted on by 'nondescriptivism' in philosophical value theory. The eighteenth-century British Empiricist philosopher David Hume is generally credited with the first explicit account of the claim that no description of a state of affairs in the world can ever, in itself, add up to a value judgement of that state of affairs: 'no ought from an is' is how Hume's "law" is often summarized. (Fulford, 2004:229)

There's a practical worry about viewing all values in the context of mental health (or in any context, for that matter) as legitimate. Forensic psychiatry often requires clinicians to help clients who have problems with violent or sexual offending. On many occasions those who abuse women and children will attempt to rationalise this via a different set of values. Some clients will attempt to justify what they have done via a set of values about the relative worth and role of women. There are clients who think that the moral prohibition on sexual relationships with young children is merely a social construct or reflects societally endorsed values and that their value set is one that is just as valid. A therapeutic challenge for forensic psychiatrists is to dis-abuse paedophiles from colluding about the validity of such values and attempting to justify their behaviour. Fulford's attempt to place all values on the same footing and to view them as not only different but 'legitimately different' is false because some values are not legitimate and there are practical therapeutic (and not only ethical) problems with viewing values in this way. However, there's a more general issue for empirical ethics about how the fact/value distinction, if indeed any such distinction can be drawn, should influence our theory.

### **Putnam on the 'entanglement of fact and value'**

A serious philosophical problem in shaping a theory about empirical ethics around the Humean version of the fact/value distinction is that there are strong arguments for thinking that no clear distinction can be drawn. In 'The Collapse of the Fact/Value Dichotomy' (2002), Hilary Putnam shows how philosophical debate about the synthetic/analytic dichotomy and the eventual abandonment of that distinction is a corollary for the fact/value distinction. The significance of the entanglement of fact and value for ethics has not been missed by those who have theorized about empirical ethics. Jonathan Ives (2014) has built on Eric Racine's moderate pragmatic naturalism (2008) and argued that we don't need to resolve the fact value problem in order to make progress with ethics or to formulate empirical ethics. Ives argues that when considering fact and value it is difficult to 'make epistemic sense of either in isolation' (Ives, 2014:303). That seems correct, but it is also important to be cognisant of different forms of value and their justification: doing this can enable us to have a more nuanced view of empirical ethics and how it is distinct from medical sociology.

As I've already suggested, Hume deduced such a stark dichotomy because of his commitment to 18th century empiricism. In effect, Hume's epistemology gave him what he took to be a true account of facts. Given the way that epistemic story worked, it was hard to see how values could be derived from it, so the fact/value distinction seemed self-evident to Hume because of what he took facts to be.

A series of problems in epistemology and the philosophy of science led philosophers to see that it was impossible to give an account of knowledge, and of scientific knowledge, that did not include values.

‘...judgments of coherence, simplicity (which is itself a whole bunch of different values), not just one “parameter”), beauty, naturalness, and so on, are presupposed by physical science, likewise many today who refer to values as purely “subjective” and science as “objective” continue to shut their eyes to this same fact. Yet coherence and simplicity and the like are values.’ (Putnam, 2002:31)

Putnam is careful to point out that he does not wish to equate epistemic values with moral or religious values. It is reasonable to suppose that these three kinds of value have different epistemic justification and will or will not be capable of being grounded in different kinds of ways. His point is that just because something doesn’t appear to be directly observable, in the way that my blue Humean ball is, it does not follow that it is not objective or incapable of being included within our realm of knowledge. The coherence and simplicity of Newtonian mechanics are features of those laws about physics and seem capable of the degree of objective description that is required by the natural sciences. Moral values, on the other hand, need a different kind of grounding and we might be less confident about their objectivity so more needs to be said about different kinds of moral value.

Meta-ethicists such as John McDowell, Philippa Foot and David Wiggins have discussed the apparent factual, or objective, nature of so called ‘thick ethical concepts.’ These are concepts that we would undoubtedly view as being evaluative, but where we do not appear to be making some kind of error to view them as truth apt:

If someone asks me what kind of person my child’s teacher is, and I say, “he is very cruel,” I have both criticized him as a teacher and criticized him as a man. I do not have to add, ‘He is not a good teacher,’ or, ‘He is not a good man.’... “Cruel” simply ignores the supposed fact/value dichotomy and cheerfully allows itself to be used sometimes for a normative purpose and sometimes as a descriptive term. (Putnam, 2002:34-35)

The point here is that there are moral values that share many of the same features as the paradigmatically factual but we do not bat an eyelid about whether or not such claims are epistemically warranted. In the context of bioethics there are many thick ethical concepts that we use without needing to be concerned about whether we’re making some kind of epistemic mistake. For example, if we see a psychiatrist who is attempting to calm a psychotic patient say something that is untrue but will put that patient at ease, we might say that this psychiatrist had been both ‘untruthful’ and ‘paternalistic.’ Concepts such as these are the bedrock upon which bioethics and empirical ethics are built. They’re also concepts that appear to be factual and evaluative: there are factual features of that psychiatrist’s behaviour that will make these attributions true or false, yet at the same time these are evaluative and ethical concepts. It might be objected that thick ethical concepts are ambiguous in that when they’re being used in a factual sense they’re not clearly normative, and when they’re being used in a normative sense they’re not straightforwardly factual. There’s something to this worry, but because the fact/value distinction tends to be presented as a dichotomy then thick ethical concepts create a significant grey area between fact and value. Furthermore, even if someone is using ‘coercion’ in a descriptive sense (i.e. that someone did something because of a threat), this is a sense that although not normative insofar as it entails that this should not occur, could not be considered morally neutral.<sup>1</sup>

VBM is a version of empirical ethics that assumes a version of the fact/value distinction that we should not accept. In effect, for it to be plausible VBM requires a dichotomy between fact and value. No such dichotomy exists because there are many values that are objective (for example the epistemic values of natural science), and there are thick ethical concepts that can be considered factual.

Putnam is correct that there are different kinds of value and that they require different kinds of justification. One defining feature of all values, and the reason why Hume included them within his category of ‘the passions’, is that they are motivating. For Hume, reason is empty and inert without motivating passion. While we should not agree with Hume’s epistemic picture, he’s correct that one defining feature of the passions (and values) is that they are normative; they give us a reason to act.

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<sup>1</sup> See Szmukler & Appelbaum (2008) for an example of how such concepts can be used.

When a scientist notes the coherence and simplicity of an explanation, she has reason for thinking that explanation good. When a music critic hears the dynamic range, precision and sensitivity to the composer's intention of an orchestral performance, she might judge that performance to be excellent. The neighbour who intervenes in a domestic dispute where a child is about to be harmed has a moral reason grounded in the importance of preventing badness. In these three cases values play a role, so we could argue that there are 'normative' elements in all three cases. Yet, the kind of normativity is different in each of the examples, the first is a scientific or epistemic norm, the second an aesthetic norm, and the third moral. As I will show in the next section, there are different kinds of normativity that can be highlighted by empirical approaches to health care.

### **Adam Hedgecoe's challenge to empirical ethics**

Empirical ethics can take a number of forms and have a variety of aims. But for many, it is driven by a concern that bioethics can become too philosophical and insufficiently grounded in real world problems. Empirical ethics can help by building scholarly inquiry in bioethics upon the concepts, problems and challenges that health care professionals face (McMillan & Hope, 2008; McMillan, 2012). A broad array of empirical methods have been proposed for doing this, but it would be fair to say that qualitative methods are used extensively, principally because they are an effective way of interacting with clinical reality.

Adam Hedgecoe has given careful thought to the problematic nature of the fact/value distinction and is sensitive to what this implies about the futility of trying to demarcate the factual elements of inquiry in bioethics from the normative. What he has in mind is the fallacious idea that social scientists merely generate empirical data about health care which is then subjected to critical normative analysis by philosophically minded bioethicists (Hedgecoe, 2007). He, correctly in my view, objects to the claim that medical sociologists are not interested in normativity and points that out that they clearly are and that there is a rich literature in sociology which does exactly that.

Medical Sociology provides thoroughly socially, culturally and politically embedded explanations for the values and actions of health care professionals. Thus if medical ethicists are interested in the lived experience of the social world of modern medicine, an obvious solution would be to read some more medical sociology, rather than look towards developing a new discipline (Hedgecoe, 2007).

Almost everything Hedgecoe asserts here is correct: medical sociology is the place to look for nuanced socio-historical explanations for why health care professionals do what they do, and also for understanding the values that lie behind this. The suggestion that those working in bioethics should make themselves familiar with classic works in medical sociology and thereby become attuned to the socially critical lens of sociology is useful (Hedgecoe, 2004). An education in philosophy should equip bioethicists with knowledge about moral theories and concepts, as well as enhancing their ability to argue and think critically, however it is less likely to attune them to the broader social, historical and economic context of bioethics and its debates. In order for bioethics to become more sophisticated and aware of the reasons why issues within bioethics become controversial and are deemed worthy of attention should follow Hedgecoe's lead because there seems much that is right about this thought.

Where Hedgecoe has made a mistake is his insistence that empirical ethics does not offer something new and distinctive to medical sociology. While it is true that sociology is normative, in the sense that it is interested in values and how they come into being, and is often motivated by a commitment to particular values (such as, for example, social justice) and the socio-historical structures that frustrate those values, it does tend to pay heed to different kinds of values from those that are at stake in a more philosophical argument about ethics. I am not asserting that we should consider the work of Hedgecoe or, for example, Fox & Swazey (1992) to lack the kind of normativity that is required for them to be placed within the canon of bioethics. Rather, I am saying that sociologists tend to argue in a different kind of way, and that they are interested in different kinds of normativity. Those who approach bioethics from a philosophically normative perspective, for example authors such as Jonathan Glover, Dan Brock, John Harris and Julian Savulescu work toward finding solutions to moral problems. Such authors will argue as cogently as they can for a moral position on a contested issue.

Of course, answers to contested moral issues tend to be provisional, revisable and are likely to remain arguable. While it's true that sociologists are interested in values and correcting injustice, ordinarily they do not engage in this kind of argument. There will be exceptions to this and there are many sociologists, Hedgecoe himself being one good example, who have a philosophical background and will engage in that kind of analysis. But in such cases we could describe their argument as being 'more philosophical' or 'more analytic' and perhaps 'less sociological.' None of these descriptions should be taken to imply anything about the relative worth of this kind of argument, nor whether it should be considered 'bioethics', but it is a different form of scholarly inquiry, which uses normativity in different ways.

Strauss and Glaser's classic sociological study involved fieldwork and interviews in which they observed the issues that arise during the process of dying in North American hospitals. From a more general interest, they refined their focus so that it studied the following questions:

What are the recurrent kinds of interaction between the dying patient and hospital personnel? What kinds of tactics are used by the personnel who deal with the patient? Under what conditions of hospital organization do these kinds of interaction and these tactics occur, and how do they affect the patient, his family, the staff, and the hospital itself, all of whom are involved in the situations surrounded dying? In finding answers to these questions, we discovered that most variations could be accounted for by what each party to the dying situation was aware of about the patient's fate. (Glaser and Strauss, 1965:8)

Issues around the end of life, how we die and what our rights should be are foundational issues for bioethics, so although Glaser and Strauss predated the invention of bioethics, few would have any hesitation about viewing a study such as this as 'bioethical'. Furthermore, the methods are very familiar and they approach this area in very much the same way that someone doing a project in 'empirical ethics' might. So, Hedgecoe's observation that there is much in common between medical sociology and empirical ethics, and his frustration that bioethicists do not draw more upon this tradition, is well founded. However, the difference is what motivated Glaser and Strauss to do this study and the explanations and analysis that follow. They're very aware that what patients should know about their death is a moral issue and it clearly is something of importance to them. But in saying that, they offer rich contextual explanations for what happens. Their explanatory model is one that emphasises the importance that institutional norms, roles and other social structures have upon the ways in which people interact. What they don't do is to analyse the ethical issues that are present in the interviews and observations and argue these out in an attempt to reach an ethical position on how dying *should* occur.

Glaser and Strauss are certainly engaged in a normative exercise; they are trying to shed light on the nature of dying in hospitals partly with the hope that this might clarify, inform and perhaps even, empower. This is fairly typical for medical sociology in that it tends to have a critical and sceptical edge; it invites readers to view issues as being more complex, less straightforward and richer. This is a kind of normativity that could be considered an 'epistemic' value. Sociological epistemic values urge the reader to see a phenomenon in its social and political context. In effect this is a kind of perceptual norm: a plea to see the context that shapes, for example, organ donation or genetic counselling.

Sociological epistemic values are different from norms about what is morally right or wrong. Clearly there's a relationship between the two, in that making claims about right or wrong and being ignorant about the relevant socio-historical context is a recipe for saying false things about right or wrong. Very often the reason why a sociological analysis is warranted is because of a perception that an area is ethically complex or problematic and this kind of inquiry is a way forward. Nonetheless, there are distinct, equally important, forms of normativity in these two perspectives. Those who approach bioethics and empirical ethics from a philosophical perspective will tend to offer an analysis that involves robust argument with ethical norms, whereas a sociological epistemic values explain and analyse in a more structural and contextual way.

## Conclusions

The fact/value distinction is an important debate if we wish to think carefully about the theoretical backdrop of approaches to empirical bioethics. The traditional empiricist version where fact and value are dichotomous is arguably untenable, and yet has shaped approaches to empirical bioethics such as VBM, and is sometimes used to argue that the whole project of empirical bioethics is untenable. Further reflection upon the different kinds of value sheds light on how it is that different approaches to bioethics can be normative, but in different ways.

Good empirical ethics is distinct from medical sociology in that it should fuse robust ethical argument with the groundedness and sensitivity to context that results from a well-constructed empirical investigation. This volume contains descriptions of many such approaches. While it is true that medical sociology is also normative, the normativity of robust ethical argument, which is arguably a requirement for empirical ethics in some forms, is different from the kinds of argument that typify medical sociology.

## References

- Ayer, A. J. 1946. *Language, Truth and Logic*. London: Gollancz
- Bosk, C. 1992. *All God's Mistakes: Genetic Counselling in a Pediatric Hospital*. Chicago: University of Chicago Press
- Fox, R. Swazey, J. 1992. *Spare Parts: Organ Replacement in American Society*. New York: Oxford University Press
- Fulford, K. W. M. 2004. 'Ten principles of values based medicine', in Radden (ed.) *The Philosophy of Psychiatry: A Companion* Oxford: Oxford University Press
- Fulford, K. W. M. 2011. 'Bringing together values-based and evidence-based medicine: UK Department of Health Initiatives in the 'Personalization' of Care' *Journal of Evaluation in Clinical Practice* 17, 2, 341-343
- Glaser, B. Strauss A. [1965] 2005. *Awareness of Dying* Aldine Transaction: New Jersey
- Glover, J. 1977 *Causing death and saving lives* Penguin.
- Griffiths, P. 1997. *What Emotions Really Are*. University of Chicago Press
- Harris, J. 2005. 'No sex selection please, we're British' *Journal of Medical Ethics* 31: 286-288
- Hedgecoe, A 2004. 'Critical bioethics: beyond the social science critique of applied ethics.' *Bioethics* 18,2: 120-143.
- Hedgecoe, A. 2007. 'Medical Sociology and the redundancy of empirical ethics', in Ashcroft, Dawson, Draper and McMillan (eds.) *The Principles of Health Care Ethics*.
- Hume, D. [1738] 1956. *A Treatise Concerning Human Nature* Lindsay (ed.) New York: J M Dent and sons
- Ives, J. 2014. 'A method of reflexive balancing in a pragmatic, interdisciplinary and reflexive bioethics.' *Bioethics* 28, 6, 302-312.
- McHaffie, H. Laing, I. Parker, M. McMillan, J. 2001. 'Deciding for imperilled newborns: medical authority or parental autonomy?' *Journal of Medical Ethics*. 27, 104-9.
- Mackie, J. 1980. *Hume's moral theory*. London: Routledge Kegan Paul.



- McMillan, J. Hope, T. 2008. 'The possibility of empirical psychiatric ethics' in Widdershoven, McMillan, Hope, Van der Scheer (eds.) *Empirical ethics and psychiatry* Oxford University Press
- McMillan, J. 2012. 'Psychiatric ethics and the methodological virtues of Bioethics.' *The Journal of Medical Ethics* 28, 194.
- Mackie, J. 1990. *Ethics: Inventing Right and Wrong* New York: Penguin.
- Moore, G. E. [1903] 1993. *Principia Ethica* Baldwin (ed.) Cambridge University Press
- Petrova, M. Dale, J. Fulford, K. W. M. 2006. 'Values-based practice in primary care: easing the tensions between individual values, ethical principles and best evidence' *British Journal of General Practice* 56, 530: 703-709
- Pigden, C. 1989. 'Logic and the Autonomy of Ethics' *Australasian Journal of Philosophy* 67: 127-151.
- Putnam, H. 2002. *The collapse of the fact/value dichotomy and other essays* Cambridge: Harvard University Press
- Racine, E. 2008. Which Naturalism for Bioethics: A Defense of Moderate (pragmatic) Naturalism. *Bioethics*. 22, 2, 92-100.
- Raphael, DD. 1969. *British moralists, 1650-1800* Oxford: Clarendon Press.
- Szmukler, G. Appelbaum, P. 2008. *Journal of Mental Health* 17 (3): 233-244

# Metaethics, relativism and empirical bioethics

Mark Sheehan

Metaethics is the study of the nature of ethics. This very broadly speaking involves consideration of the nature and existence of moral truth, moral psychology and the nature of moral concepts such as 'obligation' and 'normativity'. Some of these concepts and their relationship to empirical bioethics have been considered in other chapters. This chapter will examine another of these and perhaps one of the key issues that empirical ethics and its methodologies often run up against: the question of ethical relativism.

The initial attractiveness of ethical relativism can be seen by reflecting on apparent differences between people. People do things differently: they live their lives differently, they care about different things and most importantly they differ in opinion about what things count as right and wrong, permissible and impermissible. Most commonly, ethical relativists are impressed by these differences and think that there really is no right answer to ethics questions because the values that people hold depend on the culture in which they live or were raised. We might think of this as an 'anti-imperialist' kind of thought: Who are we to judge? Why think we know better what is right and wrong than someone else or some other culture? Why think that we can say of them that they have it wrong? These are concerns about authority, or ethical truth or 'getting it right' in ethical matters (Sheehan, 2007). When we look around and reflect on the status of our own deeply held views, in contrast with those with whom we differ, it can seem that there is very little basis for separating our views from those with whom we disagree. These thoughts might have two effects on us. They might make us feel uneasy about our convictions in this area — why are we so committed to them when there is no obvious reason that they are better than anyone else's? Second, we might, on these grounds, think that we should not judge those with whom we differ, after all, their values are as good as ours.

Before unpacking these issues and their connection to empirical bioethics and its methodologies, some distinctions are useful. First, this chapter is concerned with metaethical relativism, which is a view about the nature of ethics and most often involves questions about truth and justification in ethics. The metaethical relativist thinks that there is no absolute truth in ethics; there are only different views about what is right and wrong. This kind of relativism is to be distinguished from descriptive ethical relativism: a view about the actual variation of moral views across societies and cultures. It holds that, as a matter of fact, there is widespread divergence in moral values and judgements between the peoples of the world both currently and across time (Blackburn, 2001; Levy, 2002). This distinction and my focus on metaethical relativism are important for what follows. There are important issues involving descriptive moral relativism and some of these are closely connected to questions here, but the central arguments about descriptive moral relativism are orthogonal to the aims of this chapter. The connections that we explore below are important because they allow us to be clearer about the role and place of ethical argument in empirical ethics. By being clear about the status of metaethical relativism we will better understand the normative claims of arguments and justifications in ethics and their relationship to empirical evidence.

One final distinction: Opponents of relativism come in many shapes and sizes, but they all do think that value judgements are not relative. Someone opposing metaethical relativism will think that there are some ethical truths; that there are some values that one ought to hold regardless of who you are or where you live etc. They will think that some acts are right, and others are wrong, and that there is some account of how such rightness and wrongness might be determined. In what follows I will refer those who hold these views, and so are opponents of relativism, as objectivists. Following Wiggins (1995) a subject matter is objective if and only if there are questions about it that admit of answers that are simply and plainly true.

This chapter is comprised of three sections. In the first section I set the context for the discussion of metaethical relativism. I distinguish between two kinds of questions, empirical and normative, which

address normatively-invested concepts that are closely related to issues in bioethics and are central to issues in empirical bioethics. We will see that how we answer the normative questions makes a significant difference to how we understand the enterprise of empirical bioethics and the role that ethical argument and conceptual analysis plays in it. Metaethical relativism is seen to be a product of scepticism about providing a unique, authoritative answer to the normative questions and can have significant methodological consequences. In the second section we examine the status of metaethical relativism, looking at what can be said in its favour. The second section continues by examining the prospects for a moderate form of objectivism that is able to absorb some of the key intuitions of the relativist as well as offering a robust strategy for justification and progress towards ethical truths. The final section of the paper returns to develop some of the consequences of these arguments for empirical ethics and bioethics more generally.

### **The relevance of (metaethical) relativism for empirical questions in bioethics**

Arguably one of the key issues in any account of empirical ethics and bioethics will be the way in which that account can handle the relationship between the empirical and the ethical (Sheehan and Dunn, 2013; Dunn et al, 2012). How can we understand empirical ethics as anything other than some empirical research followed by some ethical research or vice versa? The stubbornness of this separation is clearly borne out in the distinction between fact and value or ‘is’ and ‘ought’, which is discussed in depth by McMillan (2016) in this volume.

One-way of articulating this issue is to cast them as distinctive questions or stances: the first is primarily directed at the way the world is and the second primarily directed at the way the world should be. These two questions quite quickly generate two approaches to what we might call ‘normatively-invested’ concepts.

Buchanan and Keohane provide us with an excellent example of this by distinguishing between normative and sociological legitimacy:

“‘Legitimacy’ has both a normative and a sociological meaning. To say that an institution is legitimate in the normative sense is to assert that it has the right to rule—where ruling includes promulgating rules and attempting to secure compliance with them by attaching costs to noncompliance and/or benefits to compliance. An institution is legitimate in the sociological sense when it is widely believed to have the right to rule.” (2006:405)

These meanings can be captured in the form of questions that express their empirical and normative basis: on the empirical (or sociological) side the question is ‘when *is* an institution taken to be legitimate?’ and on the normative side the question is ‘when *ought* an institution to be taken to be legitimate?’.

‘Legitimacy’ is what I have called a normatively-invested concept: a concept that is clearly and obviously tied to questions of value and meaning. These concepts, we might say, are closely connected to ethics but can have a highly contextualised content. The way in which an institution might be considered legitimate will depend on the details of context as well as the nature of the institution itself. Other concepts of this sort might be ‘authority’, ‘expert’, ‘power’ and ‘value’. In each case we can, following the distinction above, construct questions that are empirical and normative (see table 1 below).

Any account of empirical ethics or bioethics will either explicitly or implicitly have a place for these two sets of questions. Some may prioritise the empirical over the normative and others the reverse. Still others will make some attempt to show the way in which they can be combined or linked. In what follows below we explore the relationship between these sets of questions.

<b>Empirical (Sociological) questions</b>	<b>Normative questions</b>
Who or what is taken to be legitimate in	Who or what should be taken to be legitimate

context A?	in context A?
Who actually has or is given authority?	Who should have or be given authority?
How does authority work in context B?	How should authority work in context B?
Who are taken to be experts in field C?	Who should be taken to be experts in field C?
How are power relations instantiated in context D?	How should power relations be instantiated in context D?
What do people value?	What should people value?

Table 1 – Empirical and normative questions

### *Empirical questions*

Many if not all social science methodologies are designed to produce robust empirical data about the social world (though this is itself far from a simple affair – see Singh’s (2016) chapter in this volume). Through social science and its methods we can learn in great detail about the institutions, structures and relationships in society. Often these relationships involve normativity of various shapes and sizes; so, through social scientific analyses, we can clearly see how claims to authority, expertise, legitimacy or power (and so on) are made in a range of different contexts and how these claims come to be accepted in these.

We can learn, for example, how claims of expertise are made and accepted in a range of different contexts (Angell et al, 2008). Part of what we learn here is how groups of individuals (scientists, doctors, lobby groups, ethicists, etc.) make claims to be experts in a particular domain and the ways in which people more generally (the media, the public, patients, research participants) come to accept or endorse these claims. What we learn is something about the politics of claims of expertise: how groups or individuals, by making certain claims manage to appropriate the role of ‘expert’. This work builds an account of what is to be taken to be an expert and the relationship between being an expert and claims to expertise (for a discussion of what ‘expertise’ might mean in bioethics, see Edwards and Deans (2016) in this volume).

We can learn for example how research ethics committees (RECs) enact their position and role of authority through the context of their decision that they make and, in particular, the way in which they make those decisions. Through this kind of analysis we can clearly see the processes of authority being played out and reaffirmed. When these processes are challenged or contested we are also given a glimpse of the way in which the various relevant stakeholders understand that authority. This research builds an understanding of the authority that RECs are taken to have and the ways in which the politics of this authority is negotiated. This work does not, without further normative premises or assumptions, tell us who ought to be taken as experts: it does not alone address the normative question.

Perhaps most generally we might say that much of the social science that is closest to empirical ethics and bioethics consists of empirical studies examining, and developing understanding of, social and cultural practices and norms. In each of these cases however there is a crucial distinction to be drawn between the ability of this work to answer empirical questions and its ability to answer the closely related normative question. We can ask who or what *is taken to be* legitimate in a given context but we can also ask who or what *should* be taken to be legitimate in that context.

### *Normative questions*

Elsewhere I have argued that bioethics should be understood as a field that endeavours to answer practical ‘ought’ questions – these are normative questions of the kind above but with special reference to a particular practical context (Sheehan & Dunn, 2013). On this view bioethics is a normative enterprise: answering a practical ‘ought’ question requires making a recommendation or being prescriptive — it requires making a claim about what ought to be done. The adequacy of such claims will be, importantly, dependent on the extent to which the claim is explicitly justified or argued

for, as well as their engagement with other arguments and justifications. These practical ought questions, I suggest, are the primary questions of the field. Secondary questions are those that need to be answered in order to provide a satisfactory answer to the primary practical 'ought' question. It is important on this account that there is an explicit link between the primary question and each of the secondary questions. There are two substantive conditions to be met in order for a candidate secondary question to be appropriately linked to a primary, practical 'ought' question:

- (i) there should be an explicit link showing how an answer to the secondary question will help to answer the primary question; and,
- (ii) this link should engage with other strategies for answering the question by providing arguments in favour of the proposed strategy or against opposing strategies.

On this account, empirical questions in bioethics are put to work in answering the practical 'ought' question. Purely normative or conceptual questions (in ethical theory) are similarly secondary to the primary practical 'ought' question. It is easy to see how being clear about the empirical context can make a difference to what should happen. So long as we have a set of normative standards or argumentative strategies (a strategy for answering the normative question), we look to be in a position to arrive at an answer, given the appropriate empirical details.

Relativism becomes an issue when we think that the normative questions cannot be answered either in principle or pragmatically. That is, we might think that there is no single definitive answer to questions like 'who should have authority', 'who should be taken to be legitimate' or 'what people should value'. We might think that, in principle, the answers to such questions are essentially relative.

An example is useful (taken from Sheehan, 2008). What is the role that attitudes of the general public should play in settling ethically difficult policy questions? It certainly does look as though we should involve the public in some way in formulating these policies, but it would be helpful to have a sense of justification for this intuition. The metaethical relativist, who thinks that there is no reason to think that one person's opinion, when it comes to ethics, is better or more correct than any other's, might conclude that policy making is simply a matter of politics. Surveying the attitudes of the public is one kind of pragmatic move in this political context: 'we have to get things done and the only way to do this is to try to get everyone on board'. This kind of pragmatism looks very much like metaethical relativism.

In economics 'value' is often understood to be the weight or importance that people place on a certain thing, X. Value is expressed in, and captured by, people's preferences (Louviere et al, 2000). One way in which we determine the value of X is by testing how much people would pay for it or by ranking X alongside other relevant things. We can then use these individual level values to decide what policies we should adopt across society by aggregating the individual values in various ways. This is one way in which we might see the attitudes of the public playing a role in policy formation: by defining what is taken to be valued and how much.

There are two important implicit normative assumptions here. The first is that 'value' looks to be equated with 'preferences'. This view of value on its own is clearly a relativist (indeed subjectivist) one. Understanding value to be captured or reflected in what individuals prefer would seem to flatten nuances that we ordinarily take to be important in distinguishing what we 'merely' prefer from those things that we care most about, captured in the idea of our 'values'. The second normative assumption is the 'democratic' bridging premise that takes us from the aggregate data to a view about what should be done (Garrard & Wilkinson, 2005). Exactly what shape this takes can vary ranging from a strong democratic commitment which verges on an ethical principle, to a pragmatic approach which is resigned to politics without independent authority.<sup>2</sup>

Of course this adopted relativism and the corresponding bridging principle might be strategic methodological assumptions or metaethical commitments. In the former case, it might be the most convenient, most accessible or perhaps most reliable way to access empirical data on value. The 'democratic' bridging principle, however, provides an additional source of value and stands in need of

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<sup>2</sup> See Kim's (2016) chapter in this volume for an account of how strong democratic commitments can be worked into a methodology.

its own justification. If this is just what we happen to think, then we are back to a relativistic position. If it is the right or the best principle (or just the one that we ought to adopt), then it is embroiled in non-relativist claims.

### **The distinction between relativistic and non-relativistic positions in ethics**

What is at stake in the debate between the metaethical relativist and the objectivist? As we have seen above, if the relativist's view is correct, or at least if the objectivist's view is untenable, we have reason to be sceptical about making progress on the normative questions discussed above, and which are at the heart of bioethics and empirical ethics. Since metaethical relativism involves a claim about the nature of moral truth and justification, it is directly implicated in the claims outlined in the first section of this chapter. That is, the metaethical relativist directly claims that there is no answer to be given to the 'should; question of legitimacy: our answers to questions about who should be taken to be legitimate will necessarily be answers which express our values and these do not, and cannot, have any special status. It looks as though we can only rely on the empirical methodological strategies from social science in combination with careful attention to, and disclosure of, implicit normative assumptions within them.

In this section, then, we focus on the metaethical relativist's position and its relationship to other 'nearby' positions. In particular we will look, in a bit more detail, at the kinds of claims that might take us towards a metaethical relativist position. The section then moves to give an account of a moderate objectivism, which represents an attempt to soften the objectivist position in order to accommodate some of the lessons of the preceding discussions.

As we saw at the outset, the metaethical relativist thinks that there is no absolute truth in ethics; there are only different views about what is right and wrong. More substantively the metaethical relativist often has a story to tell about how we come to think that there are things that are 'really' right or wrong. For the relativists we have been considering (i.e. cultural relativists) this story suggests that what we think is right and wrong is importantly connected to, or determined by, the culture to which we belong or in which we were raised. Other kinds of metaethical relativists also think that there is no absolute truth in ethics, but might differ in their account of how we come to have the ethical views that we do. So, subjectivists typically would count as relativists; they hold that there is no (absolute) truth in ethics because these judgements are not the kind of things that are capable of being true or false (Blackburn, 1998). In this case, ethics is not relative to culture but to each individual subject (though of course an individual is likely to be influenced by their culture amongst other things).

#### *Metaethical Relativism*

As we saw above, descriptive ethical relativism is an empirical thesis about the variation in ethical systems across societies and cultures. A cursory glance at the variety of moral systems is enough to suggest that there is indeed significant variation. This matters here because if this variation is robust, we might have reason to be sceptical about truth in ethics, and so be provided with grounds for metaethical relativism.

Some apparent differences in ethical judgement can be explained by a closer examination of the context of the judgement. Sometimes they are not an instance of different values; rather, the situations in which the others find themselves have led to systematically different judgements. For example, water-related ethical norms in a desert context will be different to water related norms in a temperate climate. Not all divergence, however, can be explained like this. Sometimes cultures differ in their beliefs about the working of the world. If we believed in reincarnation as animals, we might, because of the same values we currently have about respect for the dead, have much more significant restrictions on how we treat animals. These explanations should not however lead us to think that all variation can be handled in this way: there remain a number of clear cases where the values are just different (Levy, 2002; Midegley, 1981).

In all of this we have been speaking of cultural variation as though cultures were fixed, but clearly cultures and cultural values are fluid and amorphous. The problem for the relativist, of course, is that if

'culture' and 'cultural values' are too vague or changeable, we will lose the sense of what it means for some ethical judgment to be 'true in that culture' or for the judgements that any individual makes to reflect the culture's values (Levy, 2002). However, for our purposes here our relativist need not be committed to a cultural basis of ethics. At bottom, what matters here is the way that metaethical relativism undermines the idea of absolute truth and justification in ethics. 'True for me', 'true for us' and 'true in that culture' each undermine just plain 'true'.

David Wong (1984; 1993) has developed an account of relativism that is more moderate than those considered so far. He argues that the relativist's position is typically characterised too harshly because it is assumed that

one's moral confidence, one's commitment to act on one's values, is somehow dependent on maintaining the belief that one's morality is the only true or the most justified one. (Wong, 1993:449)

This assumption suggests a tight connection between the metaethical claim concerning the truth or justifiability of moral claims and our confidence in the normative judgements we are prepared to endorse. The significance of this observation is that it softens the extent to which the metaethical relativist needs to definitively hold that there are no sources of authority or truth. Wong's point is that the conviction to act as we know to be right can, but need not, derive from a conviction about the truth of those judgements. The depiction of the relativist as someone who is unsure and uncommitted, because their values have no absolute grounding in truth, looks too harsh. In this respect, metaethical relativism may be a pragmatic or agnostic strategy.

Even with this moderation, the core of metaethical relativism remains. It is tempting to think that the variety of ethical positions instantiated in time and space give us reason to think that there is no absolute ethical truth; no authoritative standards of right and wrong — if there were, we might expect some convergence. The considerations above, however, suggest that this inference might be a difficult one to make work. More importantly, the gap between the empirical set of questions and the normative ones remains: empirical details about variation in ethics do not show that there are no right answers. Demonstrating differences does not mean that there are no real standards. There may be something that people should think, even if they do not.

#### *Objectivism and moderate objectivism*

On the opposite side of the fence, objectivists typically believe that there are moral truths, and that these truths give them the appropriate authority (or justification) to be confident of judgements in accord with their favoured account of these truths. Part of what is at issue here connects with our initial way of capturing the ethical relativist's impulse — what gives us the special status or privileged position to judge the values and practices of others; who are we to judge? One way to understand much of the history of moral philosophy is as an attempt to come up with a satisfactory answer to this question (Sheehan, 2007). In each case the quest is to find the standpoint from which to judge. Understood in this way, these objectivist attempts are responses to the relativist's position — if we can come up with a satisfactory answer to the 'who are we to judge?' question, then we seem to be in a better (or at least more justified) position in cases of conflict. The important point here is that the relativist cannot object to the objectivist by repeating the 'who are we to judge?' claim. Criticisms of these approaches, instead, need to be of the theories themselves as adequate accounts of ethics and, in particular, undermine the ability of the theory to achieve the required 'authority.'

David Wiggins has developed what we might call a moderate objectivist position that is 'softened' by the concerns raised by the relativist and which acknowledges the importance of variation and context. Given the interests of empirical ethics and the observations above, it is worth exploring this position. There are two main strands to Wiggins' position that are relevant here:

- (i) the way in which the position is softened towards some of the relativist's points and;
- (ii) the way in which the position is to be understood as objectivist.

We will deal with each of these in order.

Perhaps the key point of softening in Wiggins' approach involves the idea of authority (Sheehan, 2007). As we have seen, one way of understanding the challenge of relativism is by pointing to the way in which it undermines the authority of our own ethical convictions. In order to secure this authority, the objectivist seems required to demonstrate that ethical judgements are just like paradigm cases of judgements of fact. It looks as though what is required to regain the authority of our convictions is the ability to convince everyone. Faced with stark cultural disagreement between 'us' and 'them' about what ought to be done, the only thing that seems good enough are reasons that will convince 'them'.

Wiggins argues that this expectation is an unreasonable one (Wiggins, 1993). Instead, he suggests three options: incommensurability, perseverance and underdetermination. First it may be that 'us' and 'them' come from such different 'forms of life' (civilizations or cultures) that "any semblance of agreement on the question what one ought to do or what is good is only a semblance" (Wiggins, 1990:75). Here, the respective understanding on either side is so different that there is not enough common ground, or common language, on which to build any progress.

Second, there may be a genuine question that we share and where our disagreement is non-trivial. Here Wiggins urges perseverance. The thought is that by uncovering the 'deep' differences of perspective, both conceptual and responsive, one or both sides can come to see or understand the other's standpoint. This seems reasonably common — one finds oneself (suddenly) seeing or feeling what it is like from the 'other side'. The idea here is that perseverance would or could achieve agreement or a resolution of the dispute. Whether such a strategy works or not is more a matter of the individuals concerned and the circumstances of their involvement. In the enterprise of trying to understand one another, egos, temperament, claims of authority and attitudes of superiority can get in the way.<sup>3</sup>

Finally, there may be situations where, although there is a real question about what ought to be done, it is not clear that any of the parties are in a position to decide and to be justified — "there is no manifest possibility of any winning set of considerations ever being mustered" (Wiggins, 1990:77).

On this picture of ethical disagreement only the second option offers any prospect of resolution. The only authority that the objectivist can claim, then, is as a result of the process of perseverance, and this only after hindrances like egos and temperament have been put aside. It is in this context, on this account, that the possibility of truth in ethics arises. For Wiggins this happens when we arrive at the point where 'there is nothing else to think.' A particular claim, 'X is wrong,' is true when, after bringing to bear our full argumentative, conceptual and emotional resources, we realise that there is nothing else to think but that X is wrong.<sup>4</sup>

Wiggins (1990) uses the example of slavery to illustrate. Here there is a wealth of considerations that can be produced to show that slavery is unjust and insupportable, and these considerations are such as to show that there is nothing else to think but that slavery is unjust and insupportable. Raimond Gaita discusses this issue in a way that well illustrates the point. He writes:

"The slave owner denies that the slave has his kind (the slave owner's kind) of individuality: the kind of individuality that shows itself in our revulsion in being numbered rather than being called by name; the kind of individuality that gives human beings the power to haunt those who have wronged them, in remorse. If the slave owner could be haunted by the slave girl he raped, then her days as a slave would be numbered." (Gaita, 2004:156-7)

What this passage, and the rest of Gaita's discussion, brings out is how the concepts of 'individuality', 'human being' and 'person' themselves are invested with an emotional and responsive power that cannot be disentangled from them. These kinds of emotions and responses are caught up with the

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<sup>3</sup> These ideas are interestingly compared with those presented by Landeweer et al (2016) in this volume

<sup>4</sup> Ives (2014) provides an interesting contrast to this position. He sees something like this point as the point at which inquiry must (temporarily) cease, justified by an appeal to pragmatism. The bioethics research endeavour is, on his account, characterised as a process of 'noble failure' and a scepticism about whether we can ever know if we have reached the point of truth. In the face of this scepticism, we are returned to a metaethical relativist position.



idea of taking someone seriously as an individual. They illustrate the full force, not of what it is to *treat* someone as a human being, but of conceiving of them as 'other to my one'. This kind of investigation of, as we might say, the psychology of the slave owners, shows how their understanding of those who were their slaves failed to approach their conception of those who were 'fully human'. It trades on an understanding of the full range of our evaluative and emotional resources and seeks to show how these resources cohere. In the face of this understanding and in the face of this diagnosis of the slave owner, we are to see that there is nothing else to think; the slave owner is simply, and truly, wrong.

Importantly, what is shown by these kinds of considerations is not that there is nothing else *for us* to think, but that there is nothing else to think, *simpliciter*. The thought is that the arguments (and the whole wealth of considerations) are mounted from the level of a perspective that is not particular, that aims at an abstraction from the 'for us' to one involving simply one person to another. What is shown by these arguments is that the price of not thinking that slavery is unjust and insupportable is that one opts out of the point of view that is common between people. This common point of view is not culturally or socially specific, even though particular ways of expressing it might be.

As I have described it here, Wiggins' position first adjusts the aims of the objectivist enterprise by allowing that there are significant limits to the kind of success that can be hoped for. In cases where perseverance is called for, we can come to some ethical truths when the wealth of considerations in our ethical repertoire leads us to the view that there is nothing else to think. This moderate objectivist position represents a very serious attempt to acknowledge the ethical significance of context, practice and perspective, but at the same time offers a robust account of the methodology of ethical and conceptual argument which can claim authority in the face of the relativist's scepticism.

### **The consequences of these distinctions for empirical ethics and bioethics**

This chapter has been concerned with the relationship between empirical ethics and bioethics and the particular metaethical position of ethical relativism. We have seen that if the relativist's view is correct, or at least the objectivist's view is untenable, we have reason to be sceptical about making progress on the normative questions that lie at the heart of bioethics and empirical ethics.

This is why the challenge of relativism matters. If empirical ethics or bioethics purport to do ethics, to provide us with some answers to explicitly normative questions, they must engage in claims about what should be done, how we should think about things or what the right processes are. In short, answering normative questions requires providing normative answers. However, as soon as these kinds of answers are given they are then subject to the relativist's sceptical question on authority: what gives your answer authority?

The previous section of this chapter concluded with Wiggins' broad account of a moderate objectivist position. This position I suggest can provide an account of the enterprise of ethical and conceptual argument that aims at the kind of authority that answers the relativist's challenge. In what follows I draw the elements of this account together to say something about a methodology that can meet the relativist's sceptical challenge.

Broadly speaking, ethical or conceptual arguments provide the tools for a claim to be justified. The extent to which a claim counts as a satisfactory answer to a normative question is to be judged in the light of standards of reasoning that apply to arguments generally. These standards are derived from the appeal that such arguments make to reasons that apply to all agents independently of context and as possessors of the ability to reason. That is, arguments function by making an appeal to general features of agents:

So the reasons anyone should accept that q follows from 'If p then q' and p are reasons that apply to him or her in virtue of his or her logical or reasoning capacities generally — those features that he or she holds in common with all beings capable of logic and reason (Dunn et al, 2012:469).

When we engage in ethical or conceptual argument of the kind that is relevant here, we are constructing a series of premises or considerations that make reference to these general or abstracted features of agents, and which combine in standard ways to imply a concluding claim.

These ethical or conceptual arguments, our justificatory tools, are embedded in the context of dialogue and perseverance suggested by Wiggins. When perseverance fails or the context is underdetermined or incommensurable, it is likely to be because of the complex interaction between the individuals involved, the circumstances of their involvement and the context of the argument. So there will be some people for whom our arguments and considerations have no 'grip', and there will be some who refuse to try to see or refuse to engage. Importantly there will be some who are embedded in their, or their culture's, way of viewing the world – they will be unable or unwilling to try to conceive of people or contexts from the point of view that is common between people. We will of course need to be on our guard that we are not too comfortable or too 'in' so that our claims to ethical truth end up being claims of truth 'for us'. In part, the openness and critical stance that is implicated in Wiggins' perseverance situation is helpful.

It is important to see how any of these failures or breakdowns in the dialogue about what ought to be done feed back into the standards of argument and analysis, and show that the arguments are not up to scratch. This point is often missed. Insofar as an argument (or claim, or set of reasons) that I present is limited by, or entrenched within, my own view or my own perspective (and so fails to make the kinds of abstractions at which it aims), it fails as an ethical or conceptual argument which can make the kinds of claims we are considering. Pointing out that the argument (rather than the arguer) is in a certain important way constrained by presupposing features of a certain class or race or historical period, or that it relies on empirical or conceptual mistakes, is again to point out a failure to meet the required standard.

These arguments and considerations, as I have observed above, are mounted from the level of a perspective that is not particular, which aims at an abstraction from the 'for us' to one involving simply one person to any other. The process of abstraction from the particular context and the particular individual is important here. If the premises of an argument appeal to a feature of a situation that narrowly applies, it looks as though the acceptability of that argument will be similarly narrow. As a strategy, abstraction looks to be a useful one: if I want my claims to apply as broadly as possible, I should ensure that they rely on features that are as broad as possible.

Neither Gaita nor Wiggins seek to depersonalise or decontextualize this reasoning or dialogical process in the way that some forms of abstraction might; they both rely on very political and embedded accounts of the way ethical dialogues take place. Wiggins speaks of coming to see or feel what it is like from the other side. He also clearly implies that the individual foibles (ego, temperament and the like) of those in dialogue need to be managed. Gaita makes a good deal of the emotional and responsive power that is caught up in taking someone seriously as an individual. The abstraction that is implicated in these accounts, and endorsed here, is not one that is removed or isolated from the context and the human condition but is, crucially, recognised in it.

This account of ethical and conceptual argument that takes place in ethics and bioethics is intended to represent a methodology or an approach to answering questions of a certain (normative) kind. It is a strategy for getting clear on the concepts that are in play in the particular context, and for working through the nature and structure of the reasons and justifications that are possible (or available) for agents and their actions in those contexts. As such it represents a form of practically and contextually oriented abstraction and argument that is embedded in the human exchanges and behaviours that are the essential focus of normative claims. The techniques and standards that come with this approach are not mysterious or new: the standards of reasoning, formal and informal logic and argument are well known; and while it is easy to find disagreement in places, these disagreements almost always trade on agreement elsewhere.

Part of the interest for empirical ethics and bioethics in Wiggins' moderate objectivism is the way that it challenges the sceptical claim itself. The relativist cannot see how ethical and conceptual arguments (or any strategy for that matter) can have the kind of authority that bare physical facts might be taken to have, or could be capable of persuading all-comers of their truth. Wiggins' suggestion is that we

need not aspire to anything quite so grandiose: we can aspire to truth and, he thinks, sometimes achieve it without thinking that we will find it everywhere.

## References

- Angell, E. L., Bryman, A., Ashcroft, R.E. & Dixon-Woods, M. 2008. An analysis of decision letters by research ethics committees: the ethics/scientific quality boundary examined. *Quality and Safety in Health Care* 17: 131-136.
- Blackburn, S. 2001. Relativism. In *The Blackwell Guide to Ethical Theory*, Hugh LaFollette (Ed.), Blackwell: Oxford, 38-52.
- Blackburn, S. 1998. *Ruling Passions*. Clarendon Press: Oxford.
- Buchanan, A., Keohane, R.O. 2006. The legitimacy of global governance institutions. *Ethics & International Affairs* 2006; 20:405–37.
- Collins, H. & Evans, R. 2007. *Rethinking Expertise*. Chicago: The University of Chicago Press.
- Dunn, M., Sheehan, M., Hope, T. and Parker, M. 2012. Towards methodological innovation in empirical ethics research. *Cambridge Quarterly of Healthcare Ethics*, 21(4): 466-480.
- Edwards K, Deans Z. 2016. Empirical Bioethics and the role of the ethicist in policy making: Politics, Authority and Expertise. This volume
- Gaita, R. 2004. *Good and Evil: An Absolute Conception* (2<sup>nd</sup> Ed.), Routledge: Oxford.
- Garrard, E. & Wilkinson, S. 2005. Mind the gap: the use of empirical evidence in bioethics. In M. Häyri, T. Takala and P. Herissone-Kelly, P. (eds.), *Bioethics and Social Reality*. Amsterdam: Rodopi Publishers, 2005: 77-92.
- Ives, J. 2013. A method of reflexive balancing in a pragmatic, interdisciplinary and reflexive bioethics. *Bioethics*, 28(6):302-312
- Kim, S. 2016. Theory and Practice of Democratic Deliberation in Empirical Bioethics Research. **This volume.**
- Landeweer, E, Molewijk, B, Widdershoven, G. 2016. Moral improvement through interactive research: An example of dialogical empirical ethics. This volume
- Levy, N. 2002. *Moral Relativism: A Short Introduction*, Oneworld Publications: Oxford.
- Louviere J, Hensher DA, Swait JD (2000). *Stated choice methods: analysis and application*. Cambridge: Cambridge University Press.
- McMillan J. 2016. Empirical Bioethics and the fact/value distinction. This volume.
- Midgely, M. 1981. On Trying Out One's New Sword. In *her Heart and Mind: The Varieties of Moral Experience*, Harvester Press: New York.
- Sheehan, M & Dunn, M. 2013. On the Nature and Sociology of Bioethics. *Health Care Analysis*. 21:54–69.
- Sheehan, M. 2008. Ethics and Policy: Dealing with Public Attitudes. *Radiation Protection Dosimetry* 129: 295-298
- Sheehan, M. 2007. Moral Relativism. In R. Ashcroft, A. Dawson, H. Draper and J. McMillan. *The Principles of Biomedical Ethics* (2nd Ed.) Wiley and Sons, 2007
- Singh, I. 2016. Evidence, Epistemology and Empirical Bioethics. This volume

Wiggins, D. 1995. Objective and Subjective in Ethics, with Two Postscripts about Truth. *Ratio* (New Series), 8, 243-58.

Wong, D.B. 1984. *Moral Relativity*. University of California Press: Berkeley CA.

Wong, D.B. 1993. Relativism. In *A Companion to Ethics*, Peter Singer (Ed.), Blackwell: Oxford, 442-50.

Wiggins, D. 1993. Cognitivism, Naturalism, and Normativity: A Reply to Peter Railton. In *Reality, Representation and Projection*, Haldane J and Wright C (Eds.) Oxford University Press: Oxford.

Wiggins, D. 1990. Moral Cognitivism, Moral Relativism and Motivating Moral Beliefs. *Proceedings of the Aristotelian Society*, 91, 61-85.

# Empirical Bioethics and the role of the professional ethicist in policy making: Politics, Authority and Expertise

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Zuzana Deans

There is growing consensus that empirical ethics is the appropriate method for reaching answers to practical moral questions, with the debate centering on details of correct methodology. In the research context, there has been much discussion of how to bring together the various disciplines and actors that contribute to empirical ethics. Specifically, scholarly work to date looks at how to reconcile the empirical 'is' of the social sciences with the normative 'ought' of philosophy, and how lived experience should shape our understandings of moral principles.<sup>5</sup> One of the central goals of such work is to produce arguments for public policy that are effective and justified in virtue of being grounded in the practical context in question.

One way to understand the 'rise' of empirical bioethics is as a response to concerns about legitimacy and expertise in relation to public policy, with much of the empirical bioethics literature striving to develop a way of doing bioethics that gives it a legitimate place at the policy table. One analogy worth making is with the Patient and Public Involvement (PPI) movement in health care research more generally, which "is underpinned by the notion that people who are affected by research should have a right to have a say in what, and how, research is undertaken." (Ives et al, 2012:181) This movement suggests that, in health care research, the professional expertise of the researchers alone is not sufficient to make research relevant, useful or legitimate. What is needed is input from 'lay' persons, who can contribute to the research process the relevant and vital expertise that comes from being a service user. Similarly, accounts of empirical bioethics can be seen as a challenge to the traditional, and arguably illegitimate, power dynamic in bioethics research, in which the professional bioethicist thinks "hard in a special way" (Hedgecoe, 2004:138) using her finely tuned capacity for rational thought, and pronounces on the correct course of action. The methodological accounts showcased in this volume are, at least in part, based upon an implicit critique of philosophical ethics understood in this way.

Before making claims about what the ethicist ought to bring to the policy table, we need first to be sure her place there is legitimate. In this chapter, we assess the legitimacy of appointing ethicists to policy committees, first making an argument for how their role can be justified, and then suggesting how empirical ethics research can enhance this role. We consider whether the ethicist's place on the committee is justified by any expertise she may have to offer, and then go on to articulate a framework of political philosophical positions that justify her role in policymaking. While the ethicist is not given special authority over other members (e.g. power to veto), suggesting that she is not seen as morally authoritative, she and other committee members do exercise significant political authority in determining binding regulations on behalf of the state. We take it as a crucial and unmet challenge to this institutional set-up to explain why we should entrust such decision-making to the ethicist in particular and such an appointed committee more generally. We show how, from the perspective of many of these political philosophical positions, familiarity with and use of empirical ethics research may usefully strengthen the justifications for the ethicist's influence on policymaking.

This explication of the proper role of the professional ethicist – understood as the influence that the ethicist should exert on the creation and substance of policy – depends largely on what type of

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<sup>5</sup> See MacMillan's (2016) and Sheehan's (2016) chapters in this volume.

authority the ethicist possesses. As previous scholars tend to derive the type of authority ethicists can and ought to lay claim to from the type of expertise they possess, we begin by reviewing arguments about ethics expertise. However, we argue that even resolving this entrenched disagreement on the ethicist's expertise cannot settle the question of what authority they should exercise in the policymaking context.

Instead, we observe that the ethicist serving as a public appointee to a policy committee wields *de facto* political authority. That is, policy committees that act as an arm of the state produce binding regulations for other citizens. In doing so, the committee is responsible for deciding whether to coercively restrict or require certain behaviour by individuals. The determination of the role of the ethicist in the context of a policy committee, then, depends primarily on an account of legitimate political authority, rather than on an account of the expertise of the ethicist. Although we lack the space to articulate such an account here, we outline the consequences of various potential accounts of legitimacy for the role of the ethicist.

Finally, we consider how empirical ethics may enhance these justifications for the role of the ethicist. Again, carving out a special place for empirical ethics requires first the endorsement of a particular account of political legitimacy in regulatory decision-making. Yet we illustrate how, on some such accounts, empirical ethics may indeed enhance the justification for the ethicist's influence on policymaking.

Three brief clarifications of context and terms are useful. First, by empirical ethics we crucially do not refer to normative conclusions drawn solely on the basis of public opinion polling or simple surveying of what practitioners or patients are doing in practice, although most of the policymaking bodies that we discuss herein consider such empirical evidence (often through PPI). Rather, we refer to the development, deployment, and testing of normative arguments close to practice, which may be done in a variety of ways to a variety of ends. This account of empirical ethics focuses on the ways in which systematic study of the practical context in which our ethical arguments are meant to function contributes to the overarching objective of bringing our lived realities in line with justified, moral practice.

Second, by 'professional ethicist' we refer to an individual ethicist who is employed or voluntarily serves on a committee to bring ethical considerations to bear upon practical situations beyond the considerations voiced by other committee members. We consider an ethicist to be a scholar of the normative demands of morality, identified by peers (typically university academics) as specialists in this field. The disciplinary backgrounds of these individuals vary considerably and include, for example, moral philosophers, theologians, lawyers and social scientists.

Finally, we focus our inquiry on ethicists that sit on deliberative bodies responsible for setting regulations on a specific policy matter for a particular political society, such as the UK's Human Fertilisation and Embryology Authority (HFEA) and various committees of the UK's National Institute for Health and Care Excellence (NICE). Beyond such statutory bodies, we also consider advisory bodies and short-term commissions that are convened by the government but whose recommendations are subject to approval or rejection by separate, executive decision-makers. For brevity, we will use the term 'policy committee' to include all of the above. We provide justification for considering executive and advisory bodies in tandem in section two below.

### **What Expertise Does the Ethicist Possess?**

Previous attempts to carve out the role of the ethicist generally focus on whether an ethics expert can exist, and what exactly she would be an expert in. While most agree that in order to claim expertise, the ethicist must bring some skill or information above and beyond what the layman offers to the conversation, there is much disagreement on what exactly this expertise consists in. This robust disagreement on the ethicist's expertise is largely rooted in an entrenched debate about whether ethicists have privileged access to moral truth or know better what ought to be done. In other words, despite there being fairly widespread agreement about the observable skills or abilities of a good ethicist, there is heavy disagreement on whether these skills allow the ethicist better access to moral

truth and thus whether she has some special claim to moral authority in virtue of this expertise in what ought to be done.<sup>6</sup>

The implication is that if ethicists do have expert knowledge or skills such that they are better able to access moral truth, there may be occasions in which laymen ought to defer to their judgment. For instance, Peter Singer, in his defence of moral philosophers as moral experts, argues that philosophers should be better able than others to reach “the right decision, or at least a soundly based one,” (Singer, 1972:116) suggesting his conviction that we can come to know what is the objectively right thing to do through skilled and careful philosophical argument.

Lisa Rasmussen, on the other hand, distinguishes between two types of expertise that track the disagreement on access to moral truth: hard ‘moral expertise’ akin to Singer’s definition and a softer ‘ethics expertise,’ where she uses the terms ‘moral’ and ‘ethics’ merely as a heuristic. She defines moral expertise as “the ability to resolve dispute on a moral issue by rendering a decisive opinion” (Rasmussen, 2011:651). It is the status or position of the moral expert that gives her this ability. She notes that followers might accept the Pope as a moral expert due to their belief in his special access to moral truth through his connection to God’s will, but rejects the possibility of moral expertise for ethicists. In contrast, she defends and describes ethics expertise as the ability to give non-binding “recommendations grounded in a pervasive ethos or practice within a particular context” (Rasmussen, 2011:650), such that an ethics expert could aid others in understanding, for example, the arguments and principles supporting or opposing a particular position, the rationale behind the law and regulations relating to it, and the relevant academic debate.

Scot Yoder suggests that expertise hinges on one’s ability to provide justification for a claim, regardless of whether this justification results in a claim that is known to be true: “[E]thics expertise is not based on the truth of one’s judgments but on one’s ability to provide a coherent justification for them” (Yoder, 1998:13). In other words, the ethicist’s expertise lies in providing arguments that adhere to recognised standards of justification. This is compatible with Rasmussen’s account, which allows for an expertise in providing guidance to practitioners on the basis of well-established, context-specific norms, while denying that such guidance will or needs to track objective moral truth.

The implicit assumption motivating this debate on the nature of ethics expertise seems to be as follows: if we can resolve the type of expertise that ethicists can lay claim to, then we can determine the validity and scope of their authority and role in public life. However, we suggest that this assumption is mistaken: accounts of the ethicist’s expertise will consistently fall short of justifying the authority and role of the ethicist in policymaking. Indeed, ethicists on policy committees are not assigned authoritative status as an ethicist (though they may be *an* authority on ethics).<sup>7</sup> Certainly, the answers to the expertise question may be somewhat determinative of the authority question.

One who believes that ethicists do not possess any of the accounts of expertise described above is unlikely to assert the authority of ethicists as ethicists; there is no reason to think that an ethicist, by virtue of her profession, can or should make authoritative judgments if ethicists have neither privileged access to moral truth nor a softer version of expertise in navigating moral issues. Assuming the ethicist does have this second type of expertise (ethics expertise), this goes some way to justifying her involvement in the policy committee on the basis of expertise in place of, for example, an elected representative or a layperson. Importantly, few deny the very substantial skill set that ethicists may possess. Indeed, while disagreeing quite resolutely on whether ethicists can possess hard expertise in what ought to be done, former accounts seem fairly well in agreement on the skills, characteristics, and descriptive expertise in moral theory that a good ethicist will possess. Singer (1972) suggests that philosophers will be better able to find, understand, and isolate relevant empirical evidence, be more familiar with moral concepts and the logic of moral argument, be more aware of bias, and have more time to think about moral issues than the average person. Rasmussen’s (2011) account of the ethicist’s expertise echoes Singer’s points, though she adds that ethicists will also be better able to

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<sup>6</sup> Of course, this debate presupposes the possibility of moral truth – see Sheehan (2016) in this volume.

<sup>7</sup> The distinction between *in* authority and *an* authority is as follows: the status of a person *in* authority (e.g. the Pope) is sufficient for others to defer their judgement to him; the ethics expert does not have this status, but instead has special knowledge or skill in a given area – she is *an* authority on the matter – such that the non-expert has reason to accept and act on the basis of the expert’s advice. See Rasmussen (2011)

offer creative solutions. Finally, David Archard – even while directly rebutting Singer’s argument – suggests a similar skill set, where philosophers are more skilled in the “systematization, clarification, disambiguation and – where necessary – modification of common-sense morality.” (Archard, 2011:125) We will return to the ways in which this expertise may be utilised in the final section, where we suggest that empirical ethics may enhance the role that the ethicist can play.

Even with a positive account of ethics expertise, further explanation is needed to justify the ethicist’s membership on a policy committee that exercises authority to mandate or prohibit action by others. It would be a mistake to think there is a direct connection between expertise and political authority. David Estlund refers to the unsubstantiated jump from expertise to authority as the “expert/boss fallacy” (Estlund, 2008:3): just because someone may know better what ought to be done does not necessarily mean she should be ‘the boss’ in regulating the choices and behavior of non-experts. To claim that those who know better ought to rule requires a justification that goes beyond the establishment and elucidation of the individual’s expertise: it requires an account of legitimate political authority.<sup>8</sup>

### **Deriving the Role of the Ethicist from an Account of Legitimate Political Authority**

As we have shown, expertise goes some way to justifying the ethicist’s role in a policy committee; she can, for example, offer expert guidance on the moral principles underlying particular issues, and can offer assessment of the most relevant arguments. However, this is not sufficient to justify the decision-making powers assigned to ethicists (as well as all other members) on policy committees. In this section we do not attempt to derive the authority of the ethicist from her expertise, but instead begin by examining the *de facto* authority that the policy committee is given. Then we illustrate how an account of the legitimate exercise of that authority will entail a particular role for the ethicist.

To understand the nature of this *de facto* political authority, it is useful to consider in more depth the policymaking context in which ethicists are generally placed, such as the UK’s HFEA and NICE’s Highly Specialised Technologies Evaluation Committee. These bodies, sitting at various degrees of arm’s length from ministers in the UK, feature central deliberative committees that are responsible for determining regulations in a specific area. They also often determine the sanctions that will be in place for individuals or institutions that violate these regulations. For example: the HFEA can revoke the license of an *in vitro* fertilisation (IVF) clinic if it fails to meet regulations and legal requirements; the Care Quality Commission and Monitor (two health services regulators) can impose financial penalties on service providers that fail to meet quality, safety, and cost efficiency requirements; the Medicine and Healthcare Products Regulatory Agency (MHRA) can prosecute drug and device manufacturers who breach regulations.

Standing advisory bodies as well as temporary commissions chartered by Parliament or departments to address a specific policy question also fall under the purview of these arguments. Although their advice is subject to acceptance or rejection by a separate, executive decision-maker, each is still convened as an arm of the state to reach policy conclusions that, if accepted, would require or prohibit certain behavior by individuals and institutions across the country. As such, their deliberative task in reaching a recommendation is quite similar to that of bodies with final decision-making and enforcement powers. As we are interested in the justified influence of ethicists on the policymaking process, these advisory bodies are analogous for our purposes to executive bodies like the HFEA to the extent that their advice is enacted.

The members of these deliberative bodies are usually appointed by politicians. For institutions that must grapple with policy around science, technology, and medicine (for example the HFEA, NICE, and the MHRA), appointees are largely scientific experts and practitioners. However, in the past few decades it has become more common for at least one ethicist to be appointed to such a body. Depending on the way in which the committee functions, this means the ethicist will either have a vote or be included in the consensus-seeking decision of the committee on matters of policy. In this

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<sup>8</sup> For example, Plato’s argument that Philosophers ought to rule in *The Republic*.



capacity, then, ethicists serve directly as decision-makers, jointly responsible with other members for constructing regulations backed by the coercive power of the state.

What implications does this political authority have for the role of the ethicist on the policy committee? This hinges on the account of normative legitimacy endorsed for the exercise of this political authority, where we follow Estlund in defining legitimacy as “the moral permissibility of the state’s issuing and enforcing its commands.” (Estlund, 2008:2) If we can formulate this account, we can judge whether policy decisions are more or less normatively legitimate, and specifically whether and how the ethicist can enhance this legitimacy.

An argument for a particular account of the legitimate exercise of political authority is beyond the scope of this chapter. We instead suggest the consequences for the role of the ethicist that follow from a few plausible accounts within the UK context, although we expect such accounts to apply in other liberal democratic societies. One popular alternative to the current *status quo* of appointed deliberative committees like the HFEA is to hive such policymaking back into Parliament. This option’s justification lies in classic arguments for representative democracy, where the enforcement of coercive regulations on a population is legitimate when those regulations are set by representatives elected by that selfsame population. On this account, the ethicist would have an advisory role, although her influence could vary dramatically. Philosopher Mary Warnock, for instance, played a powerful role in chairing the Committee of Inquiry that recommended and convinced Parliament to pass the Human Fertilisation and Embryology Act of 1990 (Wilson, 2011). However, such influence would be checked by traditional democratic pressure: Members of Parliament (MPs) would be unlikely to pass legislation recommended by an ethicist or committee if their constituencies overwhelmingly opposed such policy. In the United States, for instance, President Bill Clinton rejected the carefully constructed recommendation of his National Bioethics Advisory Commission to fund stem cell research for life-threatening or seriously debilitating conditions due to political pressure (Robertson, 1999). It is worth noting that influence could instead come from less democratic sources, such as party political pressure.

Such an account of parliamentary decision-making may be countered from a few different perspectives, each of which suggests its own account of legitimate political authority. First, there is the view that many bioethical issues, such as organ donation, assisted reproduction, genetic testing, and drug regulation, have low electoral salience; citizens, the argument goes, are unlikely to consider such issues when voting for representatives, and as such there is little reason to think that the views of MPs will track the values of the people they represent. If we do in fact think that coercive policy decisions are legitimate to the extent that they reflect the democratic will, this line of argument may recommend a public referendum on morally controversial issues that have low electoral salience. For instance, residents of Washington state voted to legalize physician-assisted suicide during their 2008 general election (Steinbrook, 2008). In such a case, ethicists would have a very limited role, only influencing policy to the extent that any other political issue campaign is able to reach individual voters through, for instance, media interviews and campaign materials.

Parliamentary decision-making might still seem preferable to this direct democracy approach if we think that legislation should not always directly reflect the preferences – particularly unconsidered preferences – of the people. MPs, in virtue of their profession, have more time to think about these issues and reach a considered opinion, perhaps even the opinion that their constituents would hold if they too had time to consider the issues. Or one might think that parliamentary decision-making would strike a proper balance between enlightened debate on an issue and consideration of the democratic will, due to pressures to be reelected that will keep the preferences of the general public in view. These two responses to the direct democracy account suggest that legitimate political authority depends, at least to some extent, on the substantive quality of decisions. In other words, the procedural, democratic origin of policy is necessary but not sufficient for its legitimacy; the decisions themselves must be well reasoned.<sup>9</sup>

A second response to the parliamentary option, with different conclusions, begins by noting that we do not always think that the decisions of individuals should be subject to the will of the democratic

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<sup>9</sup> See Scot Kim’s (2016) chapter, in this volume, for an account of how this idea can be incorporated into a methodology.

majority. We think that there are occasionally situations in which the liberties of the minority should be protected against the 'tyranny of the majority.' On this view, bioethical issues – to the extent that they fall into personal and generally private territory, like reproduction or the treatment and use of our bodies – may be the type of issues that we ought to protect from majority rule. This may require a body that is politically impartial, unlike Parliament, to consider and rule on such issues. This is one reason underpinning the current system of appointing members to deliberative regulatory committees that sit at arm's length from elected representatives.<sup>10</sup>

There are a variety of ways to structure such a deliberative committee, each offering a different role for the ethicist. First, we may think that policy on technically complex issues, like genetic engineering or human tissue storage, is best made by those with relevant scientific or technical expertise. Indeed, when building a bridge, we most likely want a group of engineers to have authority to make major technical decisions, rather than an ethicist or an MP. This technocratic approach would afford no role to the ethicist. However, for issues with a salient ethical component on which there is substantial moral disagreement, this technocratic approach should be rejected because of the expert-boss distinction discussed in the previous section: it is at least not apparent, and seemingly dubious, that expertise in the technological or scientific aspects of an emerging biotechnology should give one special authority to determine whether and why other citizens should be restricted from accessing it.

The recognition of this distinctive component of substantial moral disagreement has prompted a rich literature on a second, broad set of options for structuring deliberative committees. Responding largely to John Rawls' concept of public reason, a set of political philosophers has attempted to articulate how the state ought to formulate collectively binding rules in the face of fundamental moral disagreement. Each of these formulations, then, represents a slightly different account of legitimate political authority. Proponents of public reason, though, are united by the conviction that coercive rules must be justifiable by ideas or arguments that are on some level acceptable to all those who would be bound by those rules. For our inquiry into the role of the ethicist, one of the most important disagreements amongst public reason scholars is the extent to which the content of public reason is determined by actual deliberation as opposed to philosophical analysis. Rawls, on the one hand, idealizes the rationality of the 'reasonable persons' to whom rules must be justifiable and specifies a set of values that all would endorse, thus narrowing the substantive content of public reason (Rawls, 1996). Indeed, the content of public reason is fairly well determined by philosophical analysis following from these specifications, with little needing or able to rest on actual deliberative proceedings (Quong, 2013). In contrast, other scholars argue that the content of public reason cannot be determined prior to actual deliberation. Most famously, Jürgen Habermas' discourse theory and its application to the deliberative democratic context suggest a strong proceduralist conception of legitimacy (Habermas, 1990). On his account, philosophical analysis can only help to structure the features of a deliberative process in creating an ideal discursive space that is free and inclusive; the decisions that flow from this deliberation are legitimate to the extent that the process is appropriately structured. As such, the legitimacy of rules cannot be judged on the basis of predetermined substantive standards for the content of public reason.

This suggests two crucially different roles for the ethicist. On the Rawlsian account, the ethicist would play a substantial role in specifying and applying the content of public reason; on an extreme interpretation, an ethicist simply reflecting by herself on the characteristics of 'reasonable persons' would be able to determine legitimate policy decisions, rendering a committee deliberation redundant. On the Habermasian account, the ethicist could serve as an architect, structuring the deliberative proceedings, but only the actual process of reasoning amongst free and equal deliberators could produce legitimate decisions. Accounts of Empirical Bioethics methodology to date have tended to adopt either the Rawlsian or Habermasian approach outlined above to legitimise their normative conclusions. The Habermasian account seems most visible in accounts of empirical bioethics that Davies et al (2015) call 'dialogical' including, for example, the hermeneutic (Landeweer et al, 2016) and deliberative democratic (Kim, 2016) approaches; whereas the Rawlsian account is visible in what

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<sup>10</sup> Requiring 'political impartiality' is one of three reasons that can justify the use of ALBs in the UK. See 'Public Bodies Reform', at <https://www.gov.uk/public-bodies-reform>.

Davies et al call 'consultative' approaches including, for example, Reflective Equilibrium (Theil & Delden, 2016), Symbiotic Bioethics (Frith, 2010), and Reflexive Bioethics (Ives, 2014).

This section has endeavored to lay out the various potential roles of the ethicist that follow from different accounts of normatively legitimate political authority. As suggested in the previous section, an account of the ethicist's expertise cannot sufficiently justify her political authority, understood as her influence in determining regulations that will be backed by the coercive power of the state. Instead, an account of legitimate political authority for the types of collective decisions at stake must first be endorsed, out of which will fall a justified role for the ethicist. Importantly, this is true of the authority of the deliberative committee as a whole and that of the other individual members. This analysis has focused on the ethicist in particular in order to understand why the ethicist, as an ethicist or in virtue of her expertise in making moral arguments, might be brought to the table to enhance the legitimacy of policy decisions, rather than a lay member of the public, an elected representative, or a doctor.

### **The Role of Empirical Ethics in Public Policymaking: From justification to practice**

Even after the endorsement of a particular account of legitimate political authority and a specific justification for the ethicist's involvement that follows from this account, there is still an unresolved question of how the ethicist should best utilise her expertise in that role. As noted in section one, scholars are largely in agreement about the skills or abilities that a good ethicist possesses. These are, in brief, making and analysing logical arguments, knowledge of moral theory, sensitivity to the range of ethical considerations that an issue may raise, awareness of bias, and understanding and use of relevant empirical information. This final skill in particular seems to require further specification for the policy context: when is empirical information relevant and how should it be used? Here we consider the use of empirical ethics research as one way of understanding the relevance and usefulness of empirical information for policymaking (as opposed to, for example, anecdotal accounts or contributions through PPI).

By empirical ethics, as noted at the outset, we refer to the systematic study of the force of reasons in practice, with the goal of producing well-justified normative arguments that are both shaped by and will shape the practical context in which they are meant to function. We acknowledge, however, that there are several justifications and methodological accounts that seek to meet this goal in the most defensible way. What, concretely, does this mean for policymaking? The answer to this question depends in large part on the underpinning argument for legitimate political authority that provides the justification for the role of the ethicist and others involved in the decision-making process. For example, authority that demands direct democratic involvement in decision-making will require an ethics methodology that draws on that same democratic mandate for legitimacy; such as the deliberative democracy approach outlined by Scott Kim (2016) in this volume. Political authority that requires decision-makers to navigate in a deliberative fashion between competing experiences and attitudes that reflect different moral positions implies that those empirical ethics approaches that identify the ethicist as a moral steward between competing ethical values and perspectives is likely to be most clearly justified. The dialogical approach offered by Landeweer *et al* (2016) in this volume represents one such position, established on the same assumption that those stakeholders who stand in relation to an ethical question have relevant and important expertise that should contribute to ethical decision-making. Here, the role of the ethicist is to work collaboratively, in an interpretative fashion, to find a shared solution.

Within each of these approaches, the empirical ethicist can ensure both that the heritage of the arguments she draws upon, or any novel work she undertakes herself as a committee member, are firmly aligned with the underpinning political justification for the process of decision-making itself. Whilst this is helpful in clarifying why empirical ethics connects closely to the process of making policy, it remains uncertain precisely what else the empirical ethicist can do, in a more practical sense, to assist in the decision-making process.

One feasible way of clarifying the practical value of empirical ethics in the policy-making process is espoused within those justifications of empirical ethics that articulate the value of empirical ethics in terms of the challenges of making sound ethical arguments that have effects in the world. Dunn et al. suggest that we ought to understand the role of empirical ethics as the process of making practical normative arguments “that are both convincing...and will actually convince.” (Dunn et al, 2012:473) This claim corresponds respectively to making arguments that are philosophically sound and appropriately grounded in the relevant context, such that these arguments will have force in practice. Understanding empirical ethics in this way can assist in the practical activity of cultivating arguments with sound ethical foundations to shape policy decisions in ways that are most likely to have purchase in the world. Given that policy-making is rightly seen as having failed if the policy produced has no rational normative foundation, or if it has no practical effect in the world, this articulation of attending to justification in a very practical way within empirical ethics is of crucial importance to the activities of the ethicist working to formulate policy.

It appears, therefore, that empirical ethics offers a way of bringing empirical evidence to bear on policy such that the policy produced attends to the relevant moral justifications at stake in that context. Furthermore, to be properly executed, this approach requires an individual familiar with empirical ethics, and who is comfortable interpreting and applying empirical ethics research (that is, someone who understands the methods of collecting and analysing empirical data and relating it to philosophical moral concepts in such a way to critique and synthesize sound practical ethical arguments). The professional ethicist is well placed to fulfill this role, even if she herself does not produce empirical ethics research, although experience or training in the methodologies would be valuable.

## Conclusions

Empirical ethics has received a great deal of attention as a method in bioethics, but it has yet to make a strong impact in policy-making beyond the academic world. This is despite its central purpose of bringing together a rich understanding of the lived experience with the insight and rigorous scrutiny that philosophy has to offer, a union that seems *prima facie* fitting for public policy.

Before addressing whether and how the ethicist should incorporate empirical ethics into the expertise she brings to the policy table, we needed first to understand the normative justifications underpinning her influence on policy more broadly. We have endeavoured to show that justification for the ethicist's role on a policy committee relies first on an account of legitimate political authority, and that this account will advance different kinds of empirical ethics approaches. This depends on the form of the political authority claim and recognises that these claims to political authority are likely to be sensitive (for a range of reasons) to the concerns of, or evidence about, people in the world outside the decision-making setting in which the ethicist is situated. Second, the role she plays in this position is enhanced by her expertise in articulating practical moral reasoning in ways that are advanced by those working in empirical ethics. This requires her to produce an argument for policy that is philosophically sound and that is able to actually convince policy-makers, stakeholders, and citizens in general to act accordingly.

## **References**

Archard, D. 2011. ‘Why Moral Philosophers Are Not and Should Not Be Moral Experts’. *Bioethics* 25(3);119-127. pg. 125.

Davies, R., Ives, J. and Dunn, M. 2015. ‘A Systematic Review of Empirical Bioethics Methodologies’, *BMC Medical Ethics*. Available online: DOI 10.1186/s12910-015-0010-3

Dunn M, Sheehan M, Hope T, Parker M. 2012. ‘Towards methodological Innovation in Empirical Ethics Research’. *Cambridge Quarterly of Healthcare Ethics* 21(4); 466-480/473.

- Estlund, D. 2008. *Democratic Authority: A Philosophical Framework* (Princeton: Princeton University Press, 2008), pg. 3.
- Hedgecoe, A. 2004. 'Critical Bioethics: Beyond the Social Science Critique of Applied Ethics', *Bioethics* 18(2):1 20-43
- Frith L. (2012) Symbiotic empirical ethics: a practical methodology. *Bioethics* 26(4):198–206.
- Kim S. 2016. *Theory and Practice of Democratic Deliberation in Empirical Bioethics Research*. This volume.
- Habermas, J. 1990. 'Moral Consciousness and Communicative Action', trans. C. Lenhardt and S.W. Nicholsen. Cambridge, MA: MIT Press.
- Ives J. 2014. A method of reflexive balancing in a pragmatic, interdisciplinary and reflexive bioethics. *Bioethics*, 28(6):302-312
- Ives, J. Redwood, S. Damery S. (2012) PPI, Paradoxes and Plato: Who's sailing the ship? *Journal of Medical Ethics* 39(3):181-185
- Landeweer E, Molewijk B, Widdershoven G (2016) Moral improvement through interactive research: An example of dialogical empirical ethics. This volume
- McMillan J. 2016. *Empirical Bioethics and the fact/value distinction*. This volume.
- Quong, J. 2013. 'On the Idea of Public Reason', in *The Blackwell Companion to Rawls*, eds. J. Mandle and D. Reidy. Oxford: Wiley-Blackwell; 265-280.
- Rasmussen, L. 2011. An Ethics Expertise for Clinical Ethics Consultation. *Journal of Law, Medicine and Ethics* 39 (4):649-661
- Rawls, J. 1996 *Political Liberalism*. New York: Columbia University Press
- Robertson, J. 1999. 'Ethics and Policy in Embryonic Stem Cell Research'. *Kennedy Institute of Ethics Journal* 9(2):109-136.
- Sheehan M. 2016. *Metaethics, relativism and empirical bioethics*. This volume.
- Singer, P. 1972. Moral Experts. *Analysis* 32(4):115 - 117
- Steinbrook, R. 2008. 'Physician-Assisted Death – From Oregon to Washington State' *New England Journal of Medicine*, 359 (2008), pg. 2513-2515.
- vanTheil, G. and van Delden, J. 2016. Reflective equilibrium as a normative empirical model: The case of Ashley X. This volume.
- Wilson D. 2011 'Creating the 'ethics industry': Mary Warnock, in vitro fertilization and the history of bioethics in Britain'. *BioSocieties* 6(2):121-141
- Yoder, S. 1998. 'The Nature of Ethical Expertise'. *Hastings Center Report* 28(6):11-19

# Evidence, Epistemology and Empirical Bioethics

Ilina Singh

## Introduction

In recent years, bioethical discussions about the utility and value of empirical research have become increasingly sophisticated and diverse. Many of these discussions begin with a critique of traditional philosophical distinctions such as is/ought and fact/value as a way of defending and illustrating the value, or in some cases the necessity, of empirical approaches in bioethics (Solomon, 2005; Lawrence & Curlin, 2011; Dawson, 2013). As Leget et al (2009) have shown, these approaches are by no means uniform; one might say that approaches exist along two continuous intersecting axes - the disciplinary and the epistemological. On the disciplinary axis, sociology and analytic philosophy make up each of the ends; on the epistemological axis, descriptive and normative make up each of the ends. As a consequence of these axes, empirical ethics ranges from the use of empirical data to inform normative analysis, to descriptive sociology (about ethical or moral concerns; or about bioethics itself), to efforts to properly integrate the normative and the empirical.

In the midst of this complexity about the purpose and utility of empirical data (and some confusion about what empirical ethics “actually” is), there is nevertheless a growing sense that broadly speaking, an understanding of social context should be part of bioethical analyses. How such understanding should be achieved can be viewed as a methodological concern. In his 2012 Presidential Address at the World Congress of Bioethics, Angus Dawson went so far as to claim that “the use of empirical social scientific methods is fundamental to good ethics” (Dawson, 2013). This bold claim stops short of where this chapter begins: while “*the use of*” social science methods may be necessary to good ethics, it is not sufficient. The *good* use of empirical social scientific methods will prove fundamental to good ethics.

Acknowledgement of the value of empirical investigations in ethics is an important step away from a unitary analytic paradigm, but much work remains to be done to train a generation of empirical ethicists to be sophisticated, reflexive and rigorous methodologists. Lack of understanding of the integration of research questions, data collection and analytic methods results in a good deal of bad empirical research among social scientists, and these problems have accompanied the translation of empirical approaches into ethics (Dunn et al, 2008; Hurst, 2009; Strong et al, 2010). In the absence of proper training, there is a danger that ‘tool-kit’ approaches that require minimal training and understanding will be favoured over the more difficult route (Dunn & Ives, 2009). This chapter introduces the concept of epistemology and its relationship to empirical data collection, and illustrates the impact that methods of data collection have on the process of generating knowledge through empirical encounters. The chapter has a twofold aim: First, to challenge and critique approaches to empirical bioethics that view data collection as a process that can be practised in isolation and used to inform theorising in a linear fashion.<sup>11</sup> Second, to offer a transparent and concrete discussion that will inform and encourage readers in developing their own empirical ethics research design. To this end, many points are illustrated through examples of, and reflections on, an empirical ethics research study conducted between 2008-2012.

## The ‘empirical’ in empirical ethics

What does ‘empirical’ mean in empirical ethics? For Dawson, as for many researchers in this area, ‘empirical’ refers to social context, and ‘empirical ethics’ refers to studies in or about ethics that take social context into account. ‘Social context’, as understood here, can refer to institutional, relational,

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<sup>11</sup> Kon (2009) provides an exemplar of such a linear, “hierarchical” approach to empirical ethics.

cultural, social, spatial or virtual dimensions of human and animal life. Empirical ethics, therefore, has a broad and diverse remit, a fact that generates both opportunity and confusion.

DeVries (2004) has proposed a continuum that describes empirical research in bioethics, which includes descriptive ethics; the consequences of moral decision-making; the consequences of moral advice-giving; and the context of bioethics. This typology provides a helpful way to consider some of the kinds of ethical questions an empirical approach can answer. Its focus on context in empirical ethics, as a pre and post-hoc ground for evaluations of ethical policy and ethical claims, is highly relevant. For example, in the category 'the consequences of moral advice-giving,' projects may take the following form: X advice-giving practice/policy espouses Y virtues/ideals, and has Z expected consequences. But what is X actually doing in practice? In such a formulation, the question itself substantiates the need for empirical research and simultaneously provides a clear guide to research design –the empirical work needs to capture events, practices, attitudes and so on in a given setting, for a given population of patients, and evaluate the findings in relation to the stated ideals and intentions.

As valuable as this typology is, it neglects explication of some key concerns embedded in an empirical ethics approach. For example, an implicit or explicit interest in the relationship of context and power should, and often does, inform research questions in empirical ethics. While this relationship is implicit in DeVries's typology, it would be useful to highlight it as a core dimension of the sorts of questions that generate ethical questions that require an empirical approach.

Similarly, it would be useful to highlight more features of 'descriptive ethics'. This category is not only, or even largely, about "public attitudes" to burning ethical questions (DeVries, 2004); it is also about what is sometimes called 'ethics on the ground', or 'local ethics', that is, an interest in the ways in which moral dilemmas and ethical commitments take shape through embodied processes and practices of lived experiences in local contexts. Here, the label 'descriptive ethics' runs the danger of reinforcing unhelpful distinctions between this kind of work and 'normative' questions, where description is seen as subjective, interpretive and relativistic, and normative is seen as robust, objective and impact-full (see also Musschenga, 2005). Such problematic distinctions can be exacerbated in the context of under-specified empirical ethics research questions and research design.

### *'Data' in empirical ethics*

The broad remit of empirical ethics potentiates the full range of social science 'data,' from interviews to texts to vignettes to participant observation. Each type of data has a rich tradition of collection and analysis, and its collection is usually underpinned by a particular theoretical orientation or commitment (the relationship of theory to data collection is discussed further down). On one level, it appears obvious what constitutes 'data' in empirical ethics, even though the majority of empirical ethics studies to date do not exploit the full range of methodological possibilities. Yet there is an emerging diversity of interpretation around the 'empirical' in empirical ethics. One example of this diversity is the introduction of survey methodology as an empirical ethics approach. Here, the data is arguably rather far removed from the social context, even though it constitutes a representation of 'the social' in the form of attitudes, beliefs, biases and so forth. In general, the accusation brought against surveys is that they sacrifice a thick understanding of 'the social' for data that is 'big' and generalisable. This sort of data is unlikely to enrich ethical analysis or understanding in a deep way; however, it is able to respond to general questions about how the public view the ethics of certain practices or processes, and their moral attitudes and beliefs. In DeVries's typology, surveys could certainly provide empirical ethics data on public attitudes.

A more complicated data question arises in the context of experimental neuroethics (overlapping areas include experimental philosophy, social neuroscience and moral psychology). In this area, mind and brain are the primary empirical 'sites' under investigation, and the empirical data collected is brain data in the form of, for example, brain scans or what might be considered 'near-brain data', such as

psychological data (e.g. Terbeck et al, 2013; Cope et al, 2010). One might say that the key interest in these kinds of studies is: 'How does the brain do ethics and morality'?

Is research that operationalises the brain as an empirical site for data collection part of an empirical ethics approach? The important overlap between this kind of research and other empirical ethics research is that it is clearly data-driven. The departure from common formulations of empirical research is that it does not generally incorporate social science methods or concepts, and it does not take 'the real world' as its primary research context. At the same time, real world settings are important sites in which this kind of empirical ethics research finds both its questions and its applications. For example, research investigating the neural and/or genetic bases of aggression and criminality has implications in criminal courts and in educational settings. In these contexts, biological and brain data are being used to explain moral wrongdoing, and to predict who might be at higher risk of future morally deviant behavior (Singh et al, 2014). Similarly, empirical data about unconscious bias and decision-making are shaping arguments about human capacity for free will and moral responsibility.

([https://www.academia.edu/405647/Consciousness\\_Implicit\\_Attitudes\\_and\\_Moral\\_Responsibility](https://www.academia.edu/405647/Consciousness_Implicit_Attitudes_and_Moral_Responsibility)).

It is an open question whether the biological sites and systems should be, or can be, viewed as empirical sites on par with social sites. The importance of social contexts, power relations, embodiment and so forth that empirical ethics has acknowledged and promoted, is generally not acknowledged when notions of 'the empirical' in empirical ethics is confined to biological realms and systems. If the point of empirical ethics was to assert the importance of social context in ethics, then this branch of empirical ethics potentially puts that effort at some risk by reducing ethics and morality to the brain.

### *Posing Questions and Collecting Data*

Having considered what constitutes 'data' in empirical ethics, it is now important to consider data collection and its implications for good empirical ethics research. 'What methods should I use to collect my data?' Qualitative researchers frequently hear this question from students. However, data collection methods should not be chosen for convenience or popularity or other instrumental reasons; they should be chosen because they are considered the best possible way to achieve good answers to a particular set of research questions. But many disciplines have deeply embedded assumptions about the 'right' methods to use, such that methodology is more a function of convention than of explicit decision-making. These conventions have important benefits: they confer in-group status and increase the likelihood of acceptance in disciplinary publications.<sup>12</sup> But one consequence of conventional methodological thinking within disciplines is that not only the same kinds of methods, but also the same sorts of questions, frequently turn up over and over again.

Methodological consistency offers an important advantage in that it enables comparisons across studies, allowing analysis of trends and change over time, as well as awareness of how fine-grained changes in study design affect outcomes. And indeed, methodological consistency may exist in some or many cases because those methods are, in fact, the best way to answer a particular set of research questions. At the same time, in an inherently interdisciplinary field like empirical ethics, it is imperative to train researchers to understand the basic rationale for research methods, and the implications for knowledge production of methodological choices.

Methodological choices necessarily create epistemological constraints; that is, they narrow what can be seen, how it is seen, and therefore what can be known. Methods are like lenses on a microscope; they provide sight and focus on a target phenomenon; they enable adjustments to the level of detail that can be viewed; and without sufficient care, they can blur or distort views and interpretation. For this reason, data collection is never a neutral affair, and the researcher needs to understand the ways of knowing and seeing that a methodology confers on the empirical realm. Moreover, ways of knowing and seeing in a research context are frequently (and should be) part of a theoretical framework, which

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<sup>12</sup> See Frith's and Draper's (2016) chapter, in this volume, for further discussion around the challenges of publishing with methodologies that do not fit within a disciplinary canon.



shapes the research questions and the processes of answering them. Ideally, this theoretical framework, its epistemological commitments and their relationship to methodological choices should also be made explicit in research. For example, if I adhere to the theory that human morality is a function of innate capacities, and that immoral acts likely arise because of biological pathology, then my research into immoral acts will focus on the biological realm, and my methods will be chosen accordingly. This does not mean necessarily that I am uninterested in the social dimensions of immorality, but because I believe the primary causes of immorality to be biological, and I believe understanding of causes to be the best way to address the social problem of immorality, I focus my microscope exclusively on (probably a very small and tightly conceived) biological system. This interrelationship between theory, epistemology and data collection methods may seem obvious in this example, but it is all too rarely considered in empirical bioethics research.

These complexities in the context of an empirical bioethics approach are best illustrated concretely; the following section presents a case study of empirical bioethics research, outlining the research questions and methodological choices, and discussing their implications.

### **Research with Children on Ethical Dimensions of Stimulant Drug Medications: The VOICES study (Voices on Identity, Childhood, Ethics & Stimulants)**

#### *Background to the Study*

Attention Deficit/Hyperactivity Disorder is a highly contested disorder, because of its diagnostic ambiguity, the fact that it is often treated with stimulant drugs, such as Ritalin and Adderall, and because it raises complex questions about what constitutes 'normal' childhood behavior. The disorder is usually diagnosed in middle childhood, and in most countries approximately 75 – 80% of children diagnosed are boys. The rate of ADHD diagnoses is rising in many countries, alongside a rise in consumption of stimulant drugs. A controversial estimate of global prevalence of ADHD suggests that 5% of school-age children world-wide meet criteria for a clinical diagnosis; however, there is variation across geographic areas. (Polanczyk et al, 2007). Although the US is still the largest consumer of methylphenidate, a key ingredient in the drug used to treat ADHD, increases in ADHD medication expenditures in OECD countries (other than the US) exceed the rate of increase in the US over the past decade (Singh et al, 2013).

Ethical controversies over ADHD diagnosis and stimulant drug treatments range from concerns about medicalization of childhood to concerns about the threats that stimulant drugs pose to development of an authentic self, personal responsibility, and moral agency in children (Conrad, 1976; Mayes et al, 2008; Singh, 2012). An active and frequently polemic debate over these issues has played out in the media, blogs, journal articles and books over the past decade and more, but in all this time, there had been no systematic enquiry into children's own views of, and experiences with, ADHD diagnosis and stimulant drug treatments.

The VOICES study was born out of a simple question: Was there evidence to support claims about the moral and ethical harms of stimulant drug treatments? The project's research questions focused on authenticity, personal responsibility and moral agency because these were concerns that had been most frequently raised in the bioethics literature. Alongside these specific concerns, the study aimed to generate a broad understanding of the moral lives of children with ADHD, particularly in the context of the imposition of behavioural norms and school expectations, and the experiences of stigma. Again, the focus on these concerns was derived from the academic literature, this time primarily from the sociological literature, which has a rich history of analysis and reflection about the 'moral career' of psychiatric patients and stigma and labelling (Goffman, 1963).

In the absence of empirical evidence, we considered the concepts and theoretical claims we found in the academic literature to be hypotheses rather than realities; the study would test the hypotheses and generate empirical understanding of ethical implications and moral concerns surrounding stimulant drug treatments, as perceived, reported and experienced by children. This approach,

essentially to investigate the 'lived' or 'on the ground' ethics accompanying a medical intervention, is a key dimension of empirical ethics. Hypothesis testing (this non-experimental version) is not a necessary or even a typical feature of a 'lived ethics' study; the VOICES study could have deployed a more open-ended perspective in its formulation of research questions, allowing the relevant ethical concerns to emerge from initial data collection, as in a grounded theory (Strauss & Corbin, 1990) approach. However, in this case, pilot research had been conducted (Singh, 2007, 2010), and this research, in conjunction with extensive reading of the literature, allowed for the formulation of more specific research questions.

### *The Sample*

VOICES proceeded from the premise that research with children was the best way to examine the potential ethical and moral harms (and benefits) of stimulant drug treatments – children were, after all, the patients. The fact that children with ADHD had never been included in research of this kind before was not because their inclusion had been carefully considered and then rejected. Their exclusion was a function of an epistemological problem that has its roots in social science conceptualisations of children and childhood, and in the biological reductionism of contemporary psychiatry. Post-structuralist conceptions of children and psychiatry tended to view children as victims of techniques of 'biopower' or as 'docile bodies' (Foucault, 1994); psychiatric accounts of children with ADHD tended to put the brain before the person, viewing children's behavior as a function of a biological problem of self-control (Barkley, 1986). It is ironic (given the extensive disagreements between these two perspectives) that neither account opened a space – an epistemic surface – in which children's experiential knowledge appeared valuable or important. The contention that data collection with children was the best way to answer our research questions therefore not only unsettled the way ethics was normally done; it also disrupted knowledge-production in other disciplines.

It was always clear that the VOICES study would collect data from children, but who these children should be was not clear. Sampling outside the context of a population-based study (in which sampling is generally random) requires a good deal of thought. In clinical and medical ethics studies, for example, participants are often patients and/or patients' family members, and access and research ethics considerations require planning and discussion. While researchers will often seize the opportunity to work with a 'convenience sample,' it is important to be aware of, and explicit about, the limitations of such samples. This is particularly true in cases where the researcher is also a member of the clinical group working with the patients who have agreed to participate in the study. In addition to the staple research ethics concerns, there is also the reality of the power relationship between a researcher and patients. This relationship needs to be addressed and acknowledged throughout the research process, particularly as part of the researcher's reflexive insights into how the relationship shapes the encounter with research participants and, consequently, how it shapes knowledge production that occurs through that encounter (Singh, 2010). This kind of reflexivity about sampling and the researcher-participant relationship is essential to good research practice no matter the type of participant recruited into the study, but special attention should be paid to participants who could be more vulnerable for one reason or another.

In any kind of sample, inclusion criteria are ideally decided in relation to the research questions and the research literature. In the case of the VOICES study, the academic literature on ADHD and stimulant drugs gave rise to theoretical interests in the role of gender, culture and socio-economic status in children's experiences and perceptions; and these interests were reflected in the research questions. Our sampling therefore needed to allow analyses of these variables to take place, at least in a preliminary way. The biggest challenge was how to interpret 'culture', which we did very crudely at first by including a sample of US children and a sample of UK children in the study. We actively recruited girls into the study, and recruited from socio-economically diverse areas.

A strong steer from reviewers of the funding proposal for the study meant that we also created sub-groups of participants to account for different medication status, and we included an undiagnosed 'comparison' group. Very little thought was given at the outset as to whether these sub-groups (which suggested that comparisons across groups would be possible and desirable) made sense in the context of the study questions, interests and approach. In hindsight it is clear that we, and our reviewers, fell into positivist sampling conventions, perhaps because of all the unknowns in the study,

and because the stakes around the findings were high given the controversy around the topic. Analytically, some of the sub-groups and variables we included ended up yielding important insights; for example children with fewer socio-economic resources were more vulnerable to ethical harms related to ADHD diagnosis and stimulant drug treatments than children with more resources. But any such insights were necessarily qualified by the fact that our research design did not allow for the discernment of generalisable differences between groups, and it is possible that the focus on some of these variables distracted us, at least in the initial analysis of the data, from more relevant and appropriate insights.

### *Data Collection*

In considering our sample and our methods we had to keep in mind the capacities of our child participants and the fact that we would be asking them to engage with concepts and experiences that are difficult even for adults to understand and express. From the pilot research we had learned that children engage most authentically when they feel they are driving the action with the researcher, so we needed 'child-led' methods as much as possible. We also had a pragmatic eye on the audiences that we hoped would be interested in the study findings eventually; in our case this audience was psychiatrists and other medical professionals; bioethicists; and social scientists. These audiences had no common methodological frame of reference; in fact, they had different understandings of 'empirical evidence' as outlined above. The challenge here was to conduct a study that combined strong intellectual anchors with methodological creativity, in order to allow the findings to speak across disciplines.

Ultimately we settled on a mixed methods approach that was oriented around a 60-90 minute interview with a child. The interview itself was divided into different sections, each of which probed one main topic in which we were interested (e.g. authenticity, responsibility, etc.) and several sub-topics. Different sections employed different methods, such that in the course of the interview children were asked to engage in a variety of activities, including verbal responses to questions, drawing, sentence completions, sorting tasks, a vignette, and a standardized self-perception questionnaire. This approach allowed us not only to probe the same topic using different techniques during the interview, it also opened up a range of analytic strategies that involved quantitative and qualitative methods in a complementary way.

If the interview protocol was rather structured, it is because it over-compensated somewhat in trying to address a recurring criticism we confronted about the entire VOICES study enterprise: children could not possibly report on their moral lives or on ethical concerns in a valid and reliable way. Another version of this criticism suggested that children would only parrot back what their parents or doctors or teachers had told them. Validity and reliability are concepts that come out of the world of statistical research and reflect that world's concerns with the standardization of measurement (validity: are you measuring what you think you're measuring) and generalizability of findings (reliability: if I did this study again in a different sample, using your measures, would I come up with similar findings). Common ways of addressing issues of reliability and validity in empirical research with children is to use only standardized, validated instruments; to conduct research on children only with adult participants; to conduct research with adults and children and then to compare the findings. These approaches all severely narrow what can be known about the child, and tend to reproduce knowledge rather than allowing new knowledge to enter the frame. Standardized measures, with their *a priori* categories, values and scales, offer little innovation in a new research area.

The intention here is not to erect another argument for the riches of qualitative methods over the relative impoverishment of quantitative methods. Instead, it is to reflect on the process of methodological choices in empirical ethics against the backdrop of measurement conventions. We were aware of the problematics of reliability and validity in research with children, but we felt that the ways in which those problematics were commonly addressed would not allow us to take full advantage of the epistemic surface that had opened up – in other words, those approaches were not the best way to answer our research questions, even though they would allow us to deal with the anticipated criticism of the very idea of conducting research with children in the area of ethics and moral life.

The burden of 'reliability and validity' is greatest in areas that are new to empirical research – such as ethics – in part because there is no methodologically consistent body of work on which to base research questions and methodological choices. As we note above, this sort of consistency also has significant drawbacks; moreover, it is unclear if empirical ethics as a fundamentally interdisciplinary endeavor, ought to aim for methodological consistency. But skepticism about the relevance of reliability and validity for empirical ethics (unless empirical ethics research is using a quantitative approach in which these concepts are intrinsically relevant), does not preclude a commitment to the underlying principle of quality indicators in research, and to the importance of research that allows systematic comparisons to be made across contexts. Observing the growth in empirical ethics over the past decade, it is clear that there has not been sufficient discussion of, or attention to quality indicators. This is not the place to engage in a discussion of what quality indicators for empirical ethics research ought to be; however, as proposals for quality criteria emerge (Mertz et al, 2014) it will be important to give these focused attention and scrutiny, and, as consensus emerges, to translate these into training for empirical ethics researchers.

### **Novel methods and interdisciplinarity in empirical ethics**

The solution of a more structured protocol allowed us more control over the kinds of data we collected from children; we also asked parents to fill out standardized measures and a structured questionnaire. However, this solution also gave us less time and space for a wide-angle perspective on the moral lives of children taking medications for ADHD. As time went on in our study, we came to understand more and more how much the ecological systems (Bronfenbrenner, 1979) in which children are embedded mattered to their embodied experiences and perceptions of stimulant drug treatments. Although it was not part of our initial methodological plan, we began to investigate these ecologies by making notes about children's local areas, and by incorporating questions in our interview protocol on school environments and local history, including neighborhood, families and friends, opportunities for play outdoors, and so forth. We knew that these were important concerns because where our protocol invited children to introduce themes and ideas, these were issues they raised repeatedly.

Retrospectively, it is clear that our focus on a specific set of questions that emerged from the bioethics and sociological literature, and our choice of methodological tools, could easily have allowed us to miss the significance of this local ecology. Our methods did not require us to walk around children's neighbourhoods, to visit their schools, to talk to their friends. We were fortunate in that we had sufficient flexibility and resources to start engaging this complementary lens on our research questions early in the research process, but a proper multi-sited ethnography would provide much richer and more systematic data than we could obtain in the course of the VOICES study.

Ethnography has not been used much as an approach in empirical ethics, but this is likely to change with developments in the new field of 'moral anthropology' (Mattingly, 2012; Laidlaw, 2014). This area overlaps substantively with the subset of empirical ethics studies that seek to understand 'lived' or 'local' ethics and values, viewing the processes and practices of moral life as giving rise to ethical commitments (Parker, 2007). In addition to bringing a robust method to empirical ethics, anthropology also offers a rich tradition of reflexivity in research, through which researchers learn to consider issues of power and participation throughout the research process, but particularly in sampling, data collection and data analysis.

A main point here is that empirical ethics offers an opportunity for creative and productive integration of qualitative and quantitative methods. This is not to suggest that any combination of approaches is productive or possible in empirical ethics. There are probably some incompatible approaches. Moreover, in an interdisciplinary field, it seems important to try to prevent hierarchies of approaches from emerging, in the way that these currently exist in places in the context of the qualitative/quantitative divide. In the life sciences and in medicine, for example, qualitative research is frequently valued only as a pilot phase of a project, or as part of a side project, e.g. in public engagement, or in 'ethics.' In other words, qualitative research is not viewed as essential to the investigation of the core phenomenon. A similar concern is emerging in a subset of empirical ethics, in which empirical data is collected by one kind of researcher in order to supply a dataset for a

normative analysis that will be performed by another kind of researcher. This kind of empirical data may well be more relevant to addressing real world problems than fictional ethical cases such as the trolley problem. The problem is, again, that the integrity of the empirical data is lost when it functions as a means to an end. As we have seen in this chapter, empirical data does not represent a 'view from nowhere' – the data itself is diffused with an epistemology that has been carefully considered and crafted by researchers who produced the data. This is the case whether the data is brain scans or interviews. How will or should this story be retained as part of a normative analysis? Empirical ethics needs to grapple with this question, as part of a broader acknowledgment of the complexities of data collection and analysis in ethics.

## **Roads Not Taken**

In just about any research project, a different methodological toolkit will allow different kinds of understandings and different kinds and levels of knowledge about a phenomenon to come to the fore. This is why research questions and methods should not only refer tightly to each other, they should also be held together within a theoretical framework that proposes a vision of how knowledge generated in the current study will relate to existing knowledge, and how it furthers understanding of a given phenomenon. Empirical ethics researchers must have sufficient reflexive awareness to anticipate how different approaches open up and close down what can be known about a phenomenon.

It is instructive, therefore, to consider how the VOICES project might have achieved different data had the theoretical framework been different. As pointed out earlier, the idea of interviewing children was itself a result of a framework that views children not as submissive and docile objects of social practices and forces (as in a strong social constructivist view), but as developing agents and citizens, capable of formulating and articulating views on themselves and their moral worlds. We understood these articulations to be socially informed and developmentally nuanced, and we did not assume that young people (or anyone, for that matter) were able to reflect a social reality 'out there' that was unaffected by their perspective, status, history and so forth. The ecological paradigm allowed us to embed this theoretical understanding in our research with children. Thus our approach retained an important aspect of the social constructivist critique of scientific objectivism, while rejecting a constructivist formulation of the child as victim. On the basis of our theoretical framework, we were obliged to conduct an ecological analysis of our interviews with children, and this dimension of our research proved particularly rich and provocative (see Singh, 2011).

Another approach the VOICES study could have taken is one that foregrounded the justice and equality concerns in ADHD diagnosis and treatment, drawing on a feminist bioethics perspective (see Leach Scully's (2016) chapter in this volume). This approach might have encouraged a focus on the gender dimensions of ADHD, including the bias against boys in ADHD diagnosis; gendered assumptions inherent in 'normal' child development; inattentive type ADHD as 'ADHD for girls'. More broadly, a justice and equity perspective might have investigated constructions of 'normal' and 'disordered' behaviours and persons in ADHD, or different rates of ADHD diagnosis and drug treatment among children, based on gender, race/ethnicity, socio-economic status and geographic location.

We were not unaware of these concerns in the VOICES study, of course, but our research design did not allow for their scrutiny as primary questions. We did try to over-sample girls in the study, in order to give voice to an under-represented group; and when we had the opportunity to recruit more US ethnic minority children into the sample, we did so. Had our research design prioritised gender and justice concerns, we would have recruited more children in these under-represented groups; perhaps our recruitment would have focused on these groups entirely. Our questions would likely have changed substantively from a focus on authenticity, moral agency and responsibility, to questions concerning the construction of difference and self-representation, power relations in diagnosis and treatment decisions, and access to services; and we would probably have been more focused in our efforts to understand the impacts of labeling and stigma in ADHD. It is likely that in addition to interviewing children, we would have undertaken epidemiological analyses of diagnosis and treatment

rates, to ascertain potential population-level biases, and sites of risk and resilience in ADHD. In order to better understand the local dynamics of power, diagnosis and treatment, we may have included a set of professionals in our interview study – perhaps medical professionals or teachers.

As a result of a shift in the foundational theoretical framework, the VOICES study would have had a substantively different research design and therefore a different set of outcomes. It is useful to consider the implications of theoretical foundations early on in an empirical ethics study in order to understand how a framework could shape research questions, methodological tools and outcomes.

## **The way forward**

Empirical ethics represents a hard-fought argument about the importance of data in ethical analysis, but this should not induce uncritical, unreflexive pursuit of that data. From a methodological perspective, empirical ethics is a skill that must be taught, learned and practiced, in order to achieve requisite levels of rigor and transparency. While conceptual analysis and rigor around empirical ethics have certainly flourished in the past decade, the applied dimension of empirical ethics is still remarkably under-specified, and lacks agreed quality indicators, resulting in poor research design and in analytically impoverished, inconsistent, and unreliable research outcomes. Programmes in bioethics, medical ethics and related areas need to give more thought to the development and delivery of such training. It is not an exaggeration to say that without these and other programmatic pursuits of quality in empirical ethics, the entire enterprise may fall down for lack of rigour and value.

## **References**

- Barkely, R. 1986. ADHD and the nature of self-control. New York: Guilford Press.
- Bronfenbrenner U. 1979. The Ecology of Human Development: Experiments by Nature and Design. Cambridge, MA: Harvard University Press.
- Cope, LM, Borg, JS, Harenski, CL et al. 2010. Hemispheric asymmetries during processing of immoral stimuli. *Frontiers in Evolutionary Neuroscience*. 2:
- Conrad, P. 1976. Identifying hyperactive children: The medicalization of deviant behaviour. Lexington, MA: Lexington Books.
- Dawson, A. 2013. IAB Presidential Address: Contextual, social, critical: How we ought to think about the future of bioethics. *Bioethics*, 27(6): 291-296.
- DeVries, R. 2004. How can we help? From 'sociology in' to 'sociology of' bioethics. *J Law Med Ethics*, 32(2): 279-292.
- Dunn, M. Gurtin-Broadbent, Z. Wheeler, J, Ives, J. 2008. Jack of all trades, master of none? Challenges facing junior academic researchers in bioethics. *Clinical Ethics* 3(4): 160-163.
- Dunn, M., Ives, J. 2009. Methodology and epistemology in bioethics research: A constructive/ist commentary. *American Journal of Bioethics*. 9(6-7):93-95
- Foucault, M. 1994 *The Birth of the Clinic: An Archaeology of Medical Perception*. New York: Vintage.
- Goffman E. 1963. *Stigma: Notes on the Management of Spoiled Identity*. London: Penguin.
- Hurst, S. 2010 What 'Empirical Turn' in Bioethics? *Bioethics* 24(8):439-444
- Kon, A. 2009. The role of empirical research in bioethics. *AJOB*, 9(6-7): 59–65.
- Laidlaw, J. 2014. *The Subject of Virtue: An Anthropology of Ethics and Freedom*. New York: CUP.

- Lawrence, R.E. Curlin, F.A. 2011. The rise of empirical research in medical ethics: A MacIntyrean critique and proposal. *J of Medicine and Philosophy*, 36: 206-216.
- Leach Scully J. 2016. Feminist Empirical Bioethics. **This volume.**
- Leget, C., Borry, P. de Vries, R. 2009. 'Nobody tosses a dwarf!' The relation between the empirical and the normative reexamined. *Bioethics* 23(4):226-235.
- Mattingly, C. 2012. Two virtue ethics and the anthropology of morality. *Anthropological Theory*, 12(2): 161-184.
- Mayes, R. Bagwell, C. Erkulwater, J. 2008. *Medicating children: ADHD and pediatric mental health*. Cambridge, MA: Harvard University Press.
- Mertz, M., Inthorn, J., Renz, G., Rothenberger, L. G., Salloch, S., Schildmann, J., Wohlke, S. Schickel, S. 2014. Research across the disciplines: a road map for quality criteria in empirical ethics research. *BMC Medical Ethics*, 15(1):17.
- Musshenga, M.W. 2005 Empirical ethics, context-sensitivity, and contextualism. *J of Medicine & Philosophy*, 30: 467-490.
- Parker, M. 2007. Ethnography/Ethics. *Social Science and Medicine*. 65: 2248-2259.
- Polanczyk, G et al. 2007. The Worldwide Prevalence of ADHD: A Systematic Review and Metaregression Analysis." *Am. J Psychiatry*, 164: 942-48.
- Singh, I. 2008. Beyond Polemics: Science and ethics of ADHD. *Nature Rev Neuroscience*, 9(12): 957-964.
- Singh, I. 2010.. Cryptic Coercion. *Hastings Center Report*, 40: 22–23.
- Singh, I. 2012. Not Robots: Children's perspectives on authenticity, moral agency and stimulant drug treatments. *Journal of Medical Ethics*, 39(6): 359-366.
- Singh, I, Sinnott-Armstrong, W., Savulescu, J. (Eds). 2014. *Bioprediction, Biomarkers, and Bad Behavior. Scientific, Legal, and Ethical Challenges*. New York: OUP.
- Solomon, M. Z. 2005. Realizing bioethics' goals in practice. *Hastings Center Report*, July-August: 40-47.
- Strong K, Lipworth W, Kerridge I. 2010. The strengths and limitations of empirical bioethics. *Journal of Law and Medicine*. 18(2):316-319.
- Strauss A. Corbin J. 1990. *Basics of qualitative research: Grounded theory procedures and techniques*. London: Sage.
- Terbeck, S. Kahane, G. McTavish, S. Savulescu, J. LEVY, N. Hewstone, M. Cowen, P. 2013. Emotion in moral decision-making: Beta-adrenergic blockade reduces utilitarian judgment. *Biological Psychology*, 92: 323-8.

# Friends, Foes, Flatmates: On the Relationship between Law and (Empirical) Bioethics

Richard Huxtable

## A Tale of Two Flatmates

Lei-Kung, from China, shares an apartment with his younger flatmate Bronislawa, who is Polish. Each has their own room, into which their flatmate can venture. They drafted the rules of the flat together, dividing responsibility for shared areas, like the kitchen. Lei-Kung is primarily responsible for the rota and basic maintenance, while Bronislawa regularly cleans. The apartment occupies an urban complex, whose residents toil together on common areas, such as the stairwells; Lei-Kung and Bronislawa typically work alongside their neighbours Sachan, Theo, Pascal, and Hakym and his family. Communication is complicated by the many languages they speak, and disagreements do arise. Bronislawa nevertheless throws frequent parties for the block. Once close to Theo, Bronislawa's best friend nowadays is Pascal, who tries to get on with everyone, although his relationship with Sachan is sometimes strained.

Occasionally the relationship between Lei-Kung and Bronislawa is also tested. Lei-Kung likes to keep busy doing things; Bronislawa does too, although she is also something of a dreamer. Lei-Kung sometimes exclaims that Bronislawa is “*標 (biào)*” – a word not easily translated for Bronislawa, but which essentially means that she restricts his movement by hanging off his arm while he walks. Bronislawa, meanwhile, judges Lei-Kung to be “*kombinować*” – also difficult to translate, this suggests that Bronislawa dislikes Lei-Kung's contrived solutions to problems arising in the flat.

Each does, however, speak some of the other's language, and Lei-Kung and Bronislawa usually get along amicably, appreciating their flatmate's contributions to communal life. Perhaps their relationship will develop: from flatmates, who are occasionally foes but often friends, to, one day, spouses.

This tale of two flatmates may seem an unlikely starting place, but metaphors abound in the literature that explores the relationship between bioethics and law: they ‘share much of the same turf’ (Sullivan & Reynolds, 1998); they may be related by blood, either as ‘close but estranged cousins’ (Foster, 2009), or as twin siblings (van der Burg, 2010); perhaps they are related by marriage (Wolf, 2004); or, maybe, as Miola suggests, they are “flatmates rather than bedfellows” (Miola, 2006:25). In our tale, Bronislawa, whose name means Divine Protector, represents bioethics, while Lei-Kung, which means God of Retribution, represents law. These are our protagonists, but we will also encounter Sachan (sociable), who represents the social sciences, Theo (godly), who personifies theology, Pascal, who stands for philosophy, and Hakym (doctor) and his family (i.e. the various health sciences and allied professions).

My aim here is to contemplate the relationship between bioethics and law and, in particular, to consider what law can – and cannot – contribute to bioethics. This will involve some empirical reflection, although conceptual and normative questions will also feature, including how we should understand each domain and thus how we should view the relationship. I suggest that law's (positive) contributions can be captured by five P's, which relate to law's purpose, processes, products, practices and phrasing. Despite these areas of contribution and convergence, there is also divergence and distraction, summarised in five A's, which concern articulation, angst, action, aspiration and audience. Of course, in order to see both the good and the ill in the relationship between law and bioethics, we need first to define each of these domains.

## Bioethics as a Discipline of Disciplines



To locate “bioethics”, let us remove the “bio” prefix and first consider “ethics”, or moral philosophy.<sup>13</sup> This discipline encompasses four (somewhat overlapping) sub-disciplines: *normative ethics*, which constructs and criticises normative theories of what we should do or who we should be; *applied ethics*, which relates such theories to specific fields; *meta-ethics*, which reflects on the concepts at stake; and *descriptive ethics*, which analyses actual moral beliefs and practices (van der Burg, 2010; Dawson & Wilkinson, 2009; Nuffield Council on Bioethics, 2006).

Unsurprisingly, bioethics, which developed from medical ethics in the 1960s,<sup>14</sup> accommodates all of this work, albeit with a focus on the biosciences.<sup>15</sup> Reich (1995) defines bioethics as:

“the systematic study of the moral dimensions – including moral vision, decisions, conduct, and policies – of the life sciences and health care, employing a variety of ethical methodologies in an interdisciplinary setting” (ppxxi)

As the final clause suggests, bioethics – like the party-hosting Bronislawa – provides a meeting place. Indeed, bioethics is distinctively inter-, multi- or even trans-disciplinary, inviting in a variety of disciplines (amongst them philosophy, anthropology, sociology, psychology and theology<sup>16</sup>), each of which has its own language but which must – at least in bioethics’ gatherings – communicate with its neighbours (Callahan, 1973; Silber, 1982).

Although its contributing disciplines (like medicine) are also heterogeneous (Silber, 1982), bioethics appears a particularly broad church. So is bioethics itself a discipline? Foucault (1977) suggested that:

“The disciplines characterize, classify, specialize; they distribute along a scale, around a norm, hierarchize individuals in relation to one another and, if necessary, disqualify and invalidate” (pp223).

One of bioethics’ pioneers, Dan Callahan, noted in 1973 that disciplines involve the acquisition of professional expertise, through specific training and apprenticeships, in which particular methodologies, approaches and commitments are learnt (Callahan, 1973). But, he added, disciplines can also exhibit arrogance, insulation, neurosis and narrow(minded)ness. Four decades on, some say that bioethics still lacks the necessary unity to be a discipline (Priaux, 2013). Yet, bioethics does have many of the features - good and bad – to which Foucault and Callahan referred, including education programmes, learned journals, and professional appointments and organisations.<sup>17</sup> Despite all this, it is intriguing (or is it telling?) that many of bioethics’ practitioners decline to label themselves “bioethicists”.<sup>18</sup>

Discipline or not, we might nevertheless ponder what is distinctive about this bioethics beast. Here we re-encounter Bronislawa, and specifically her ties to Theo and Pascal. While once bioethics seemed particularly associated with theology (Freeman, 2008), nowadays it is philosophy which asserts its dominance. According to Brownsword, “as a critical discipline, bioethics tries to sort out the moral wheat from the non-moral chaff” (2008:15). In short, bioethics is ethics, which is moral philosophy, albeit visiting the realm of the biosciences.

Recalling Callahan’s concerns, some of the other contributing disciplines – notably the social sciences – have been critical of bioethics’ apparent emphasis on normative, applied and meta-ethics, at the expense of descriptive ethics (Hedgcoe, 2004). As this volume attests, the tide is turning, and perhaps necessarily so, since bioethics must engage with the real world (Stirrat, 2003). Moral philosophy helps identify “the elements of a moral position” but, Brownsword (2008) continues:

<sup>13</sup> I will use ethics and morals interchangeably.

<sup>14</sup> Histories of medical ethics include, for example, Jonsen (1998) and Freeman (2008). The precise origins of bioethics are, however, contested. See Rothstein (2009)

<sup>15</sup> Silber (1982) sees bioethics as a special case of universal ethics, rather than a special professional ethics, a point deliberately reflected in the naming of the Centre for Ethics in Medicine, in which I work: G.M. Stirrat, personal communication.

<sup>16</sup> Although explicitly selective, Silber’s (1982) list (notably?) omits law.

<sup>17</sup> Notably, Brownsword (2008) describes bioethics as a discipline.

<sup>18</sup> Bioethics’ inter-disciplinarity can cause problems e.g. in the UK Research Excellence Framework, which assesses the quality of academic work, on which basis Universities are awarded funding. Lacking their own panel, “bioethicists” return to their original disciplinary homes, hopeful that their work is not too tainted by inter-disciplinarity.

bioethics is much more proximately concerned with developing working guidance for those who wish to do the right thing but who are unclear what they should actually do in particular cases – such, for example, seems to be the inspiration for much of the interest in clinical ethics committees. (pp16-17)

Bioethics, then, has not only a theoretical but also a practical remit (Sullivan & Reynolds, 1998). Miola (2006) indicates that bioethics does its diverse work in three sectors.<sup>19</sup> At the *formal* level there are authoritative, directive professional bodies, such as the UK General Medical Council (GMC), which regulates doctors. The *semi-formal* sector is less authoritative but nonetheless influential, comprising organisations like the UK's Royal Colleges and the British Medical Association (BMA). Here we might also include clinical ethics committees and national bioethics committees (like those in the USA, Belgium and Singapore). Miola's *unofficial* sector, meanwhile, comprises the discourses flowing from the academy, as well as from pressure groups. Miola feels that the lower levels of the hierarchy should influence the upper tiers, although we might wonder why and, indeed, whether the lowest tier should be further differentiated.<sup>20</sup> It might also be notable that Miola, a legal academic, posits an organisation like the GMC – which has the force of law – at the pinnacle. How, then, might its decrees differ from those issued by law? Indeed, where and how does law fit into this whole picture?

Like bioethics, law is notoriously difficult to define (Sullivan & Reynolds, 1998). Lon Fuller, however, helpfully defines the concept of law as “the enterprise of subjecting human conduct to the governance of rules”. (Fuller, 1969:96) This is useful because it appears not to beg any questions about the (conceptual) relationship between law and ethics. Jurists have, of course, long queried whether law is, *in principle*, a moral enterprise. The legal idealists (or natural lawyers), with whom Fuller sided, perceive a necessary connection between law and ethics; legal positivists, exemplified by Hart (e.g. 1965), take the opposite view.

Alongside the conceptual relationship between law and ethics, there is also the empirical relationship to consider. Is law, *in practice*, a moral enterprise? Some legal officials think so:

“It would not be correct to say that every moral obligation involves a legal duty; but every legal duty is founded on a moral obligation”.<sup>21</sup>

Yet, given our specific interest in law's relationship with *bioethics*, we should ask: is law, in *bio-practice*, a moral enterprise?

Some would suggest that the (made) laws governing bio-practices are indeed indebted to bioethics.<sup>22</sup> “Bioethics helped to conceptualize problems, elucidate essential values, and influence the development of legal doctrines and processes”, suggests Rothstein (2008:3).<sup>23</sup> As such, meta-ethical bioethics can clarify common legal concepts, like the “reasonable man (sic)”, “intention” and “public morals” (van der Berg, 2010:2,9,23). Bioethically relevant data might also be adduced,<sup>24</sup> while bioethics' normative and applied work can provide prescriptions about, say, respect for autonomy,<sup>25</sup> and the value of human life.<sup>26</sup>

These different contributions will appear in different legal locations. Common law systems, for example, refer to written rules and to judges' rulings. So, in English law, not only will we hear bioethics' voice(s) in the commissions and reports that precede Acts of Parliament,<sup>27</sup> but we will also

<sup>19</sup> Although he considers medical ethics, his point seems equally applicable to (the wider) bioethics.

<sup>20</sup> Although each possesses a useful moral compass, pressure groups and academic scholars seem distinct. Presumably, for example, scholarship involves a particular expertise, although some resist the idea: see Huxtable (2012).

<sup>21</sup> *Instan* (1893) 1 QB 450, 453, *per* Coleridge LCJ.

<sup>22</sup> Particularly, perhaps, in medicine (Freeman, 2008). Indeed, the dilemmas that birthed bioethics also spurred the development of medical (or health care) law: see e.g. Rothstein (2009). These similar trajectories and themes (e.g. medical lawyers, like “bioethicists”, are occasionally asked what sort of lawyer they *really* are) merit further investigation.

<sup>23</sup> See also Callahan (1973).

<sup>24</sup> E.g. *Pretty v UK* (2002) 35 EHRR 1, para. 27.

<sup>25</sup> Although maybe law got there first: Annas, 1991).

<sup>26</sup> E.g. “The Philosophers' Brief”, supporting the right to physician-assisted suicide, which was submitted by Dworkin and colleagues to the US Supreme Court in *Vacco v Quill*, 521 US 793 (1997).

<sup>27</sup> E.g. The Retained Organ Commission (vice-chaired by Alastair V. Campbell) and the Nuffield Council on Bioethics contributed to the passing of the Human Tissue Act 2004, while Mary Warnock's commission led to the Human Fertilisation and Embryology Act 1990. For a US perspective, see Rothstein (2009).

encounter judicial references to the bioethical work occurring in the formal,<sup>28</sup> semi-formal,<sup>29</sup> and unofficial sectors of the discipline.<sup>30</sup> In other common law systems, like the US, 'bioethicists' have even acted as expert witnesses in court proceedings (Sullivan & Reynolds, 1998). Such jurisdictions differ from civil law systems, in which the general principles enshrined in a written code provide the primary source of law. Even in these systems, the rules can tackle bioethical matters: for example, in 2005, French law clarified the rules governing end-of-life care.<sup>31</sup>

As such, bioethics may be a discipline but it evidently encompasses a variety of endeavours, ranging from theorising in the abstract to collecting empirical data. In all of its endeavours, however, bioethics' seeks to engage with practice i.e. it seeks to work with, and speak to, the "real world". Law also performs a variety of tasks, but it too is concerned with actual practice: it seeks to issue rules that guide people in this real world. This common orientation begins to suggest that the two are related. On some accounts, (bio)ethics and law share a conceptual relationship, but even those who dispute this relationship would accept that bioethics can and does contribute to law in practice. But does bioethics itself gain or lose from its relationship with law? Let us start with the apparent positive contributions.

## Contribution and Convergence

Law's first constructive contribution to bioethics resides in its fundamental *purpose*: to guide human behaviour. Law, as the older partner (or flatmate), might have much to teach bioethics here, and bioethics should be receptive, as it too strives not merely to theorise about, but also to influence human activity. As Van der Burg (2010) says:

"Both law and morality are hermeneutic, normative, and argumentative systems or practices, their purpose being to guide human action... Moreover, both are social in character: they purport to regulate behaviour in order to make our society and our lives better" (pp18).<sup>32</sup>

Lei-Kung and Bronislawka worked together to ensure successful communal living. On Van der Burg's account, the purported differences between law and bioethics should not be inflated. Different jurists have emphasised different features of the legal enterprise, including its assumed sovereignty and its capacity to impose sanctions (Riddall, 1999; van der Burg, 2010). Yet, some sectors of bioethics – not least Miola's formal sector – need not be so different: the non-compliant doctor, for example, might be struck from the medical register. In its normative guise, meanwhile, bioethics might be deemed distinctive for its issuance of authoritative prescriptions, which are to be considered universalisable and for the good of all (Beauchamp, 1991). But law similarly seeks to be authoritative, prescriptive, general in its application (at least within jurisdictional boundaries, unless explicit exceptions are carved out), and a force for ensuring the good of society at large (van der Berg, 2010). In short, as each pursues the goal of guiding human co-existence, law and bioethics might not be so distinct.

Insofar as they share a goal, bioethics and law can also appeal to similar standards for judging the success or failure of the endeavour. Here law makes a second helpful contribution, as law is characteristically concerned with *process* (Lei-Kung, you will recall, took charge of devising the rota). As such, the standards of assessment – or the methodologies employed – in each discipline might share similarities and, again, as the older partner, law might have a great deal of experience on which bioethics can fruitfully draw.

Jurists have long pondered what it is that makes (made) law *law*, or, put differently, what makes for *good law*, if not (necessarily) in a moral sense, then in the sense of achieving law's goal. Fuller was

<sup>28</sup> E.g. GMC guidance on confidentiality was cited in *W v Egdel* [1990] 2 WLR 471.

<sup>29</sup> E.g. Guidance from the British Medical Association and a Royal College were respectively cited in *Airedale NHS Trust v Bland* [1993] 2 WLR 316 and *An NHS Trust v H* [2013] 1 FLR 1471.

<sup>30</sup> E.g. Ronald Dworkin's (bioethical and biolegal) work is cited in *Airedale NHS Trust v Bland* [1993] 2 WLR 316 and *Chester v Afshar* [2004] UKHL 41.

<sup>31</sup> Law no. 2005-370.

<sup>32</sup> See also Maclean (2008)

joined in this quest by theorists interested in the 'rule of law' and 'legal rationality' (Huxtable, 2012). Fuller's (1969) 'internal morality of law' accordingly included such norms as clarity, consistency and coherence between the law-as-stated and the law-as-applied, without which law could not hope to guide its subjects. Similar questions arise about what we might call the 'internal morality of bioethics'. Those interested in the standards associated with (good) bioethics – a bioethics that achieves its goal – have identified markedly similar norms, again including consistency, clarity and coherence (for example: Regan, 2004; Dawson & Wilkinson, 2009; and related inquiries into the internal morality of medicine: Veatch and Miller, 2001).

Certainly, in both disciplines, critical questions are asked about the ultimate ends of the particular endeavour. Some jurists have insisted that law entails a particular set of moral commitments (Brownsword, 1991), while some bioethicists urge adherence to a given normative theory (Arras, 2013; van der Berg, 2010). But many of the aforementioned norms (clarity, consistency and the like) are merely formal, instrumental or procedural – and it is here that law seems particularly well-equipped to educate bioethics. Law is experienced in issuing judgments on particular situations, by reference to guiding principles and to the situation itself. Law tackles the case and the doctrine, the latter becoming the principle in bioethics' language. In both disciplines bottom-up and top-down approaches feature. There are, of course, differences within each discipline: a civil law system might favour a top-down (doctrine-led) approach, rather than the more mixed approach we might encounter in a common law system; in bioethics, meanwhile, casuists might work from the bottom-up, while those beholden to particular principles might prefer to work down to the case in question. But, whichever extreme is preferred (and there will be middle-ground positions<sup>33</sup>), law will have important insights to offer.

To illustrate these observations, consider the common ground between common lawyers and bioethical casuists: each takes an approach that is "inductive and particularist, and, it would appear to be, dismissive of principles" (Freeman, 2008;7). Yet, this is not the whole story, as Annas, commenting on the US, hints when he says that

law's primary contribution to bioethics is procedural. Lawyers are expert at procedure. The common law itself is based on deciding individual cases and using these cases as the basis of creating law. Bioethics has adopted this technique (Annas, 1991, quoted in Jonsen, 1998:343).

Annas here appears to be describing the way in which particular rulings 'create law' by generating rules and, indeed, wider legal doctrines.<sup>34</sup> As such, the principle-generating bioethicist could also find helpful precedents in the story of the common law.

Precedent is, of course, crucial in the common law. Yet, although the approach is potentially conservative in its adherence to decided cases - and thus the past (Freeman, 2008) - changing times can mean changes in the law.<sup>35</sup> Officials working in a common law system will therefore tack between the case arising and the overarching doctrine or principle. This two-way process appears increasingly popular in bioethics too, not least with those who adopt Rawls' (1972) 'reflective equilibrium'.<sup>36</sup> The method involves working back-and-forth among our considered judgments about particular cases, the principles or rules that we believe govern them, and theoretical considerations, making adjustments along the way, with the aim of achieving coherence between them. Used by Rawls in his analysis of justice, bioethics' embrace of reflective equilibrium is evident in, for example, its deployment in Beauchamp and Childress' (2013) principlist approach. Furthermore, and of particular relevance here, reflective equilibrium has been promoted as a methodological approach to conducting empirical bioethics research, by which theory and data might be combined (Theil & Delden, 2016; DeVries and Leeuwen, 2010). As the common law has long used such a method, albeit not by name, here too we might expect law to make a valuable contribution to bioethics, not least to the aforementioned debates about methodology in bioethics, which with this volume is concerned. Indeed, the ideas might usefully

<sup>33</sup> See further the discussion of reflective equilibrium, below.

<sup>34</sup> Of course, legal doctrines might also develop from other legal sources, such as Acts of Parliament: see e.g. van der Burg (2010).

<sup>35</sup> E.g. "Social customs change, and the law ought to, and does in fact, have regard to such changes when they are of major importance", *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] AC 112, 171, per Lord Fraser.

<sup>36</sup> See also van der Burg (2010).

transfer in both directions. Empirical research in law (such as socio-legal studies) is (like bioethics) backed by training programmes, journals and organisations, but remains relatively new and it lacks an agreed meaning or scope; perhaps, then, the insights offered in empirical bioethics research might in turn contribute to the evolution of empirical legal research (Genn & Partington, 2006; Watkins & Burton, 2013).<sup>37</sup>

Returning to law's contribution to bioethics, and specifically to law's proceduralist bent, we should note that procedure also features elsewhere in bioethics' business, so there will be other ways in which law might fruitfully contribute. Those in the unofficial sector who advocate a proceduralist bioethics – promoting, for example, 'accountability for reasonableness' (Daniels & Sabin, 1997), or 'principled compromise' (Huxtable, 2012) – could benefit from law's experiences,<sup>38</sup> as might some of those working in bioethics' semi-formal sector, such as on clinical ethics committees (McLean, 2008). In short, as a forum in which process is king, law might helpfully guide its younger cohabitee.

But law can also contribute in substance, not merely in form. Put simply, law's *products* provide work for every sector of bioethics, from the academy to the committee. Law's edicts will often say something on which bioethics will also have an opinion (or, more likely, opinions plural). So, for example, many – maybe all – medico-legal rulings will include or invite ethical evaluation (no matter what some judges say).<sup>39</sup> The unofficial, academic sector will accordingly take to the journals to reflect on legal developments at home and away, while occupants of the other sectors might have cause to revise the guidance they issue.<sup>40</sup> This interplay between bioethics and law seems strikingly apparent when the end(ing) of life is in view (Sullivan & Reynolds, 1998; Coggon, 2010). The US case of Karen Ann Quinlan,<sup>41</sup> in the 1970s, appears a pivotal moment in the development of both disciplines (Huxtable, 2007). Here, for the first time, a court contemplated terminating the life-supporting treatment being provided to an incapacitated patient. Citing a proposal from an academic lawyer (Teel, 1975), the judges even explicitly created (semi-formal) work for bioethics, by advocating the creation of clinical ethics committees. Whether it is adjudicating on matters of life or death, law evidently provides many of the raw materials for constructing bioethics.<sup>42</sup>

Yet, to change metaphors, law does more than serve up the morsels for moral mastication: law also checks that bioethics' recipes are palatable. Law thus provides a testing ground for the *practice* of bioethics. Law is inherently empirical in orientation: its edicts must have purchase in the real world. Many bioethical issues have indeed been tested in legal claims: "law is experienced with analysing and solving social problems" (Freeman, 2008;6). Law sometimes *does* bioethics and, in doing so, it is normatively open (van der Burg, 2010); it is "ready to take on ethics if that is what gets served up to it for the making of decisions" (Callahan, 1996;34). Law can, therefore, test out bioethics' concepts (for example, beneficence becomes 'best interests' in the lawyer's lexicon), as well as its (action-directed) normative theories, like deontology and rule-utilitarianism. Law is, after all, replete with rules and devoted to duties, so the bioethicist may see in law different ways in which a particular normative commitment could (not) or should (not) be worked through.

Whether law gets things right (in some sense) should not detract from the fact that law has to put its morals where its mouth is: law cannot merely theorise, it must also *decide* (Rothstein, 2009; Sperling, 2008). For some, this makes law the senior partner to bioethics (Foster, 2009). As McLean (2007) says:

irrespective of the ethical views of decision-makers – legal or medical – there are rules under which they must operate [which] are superior (in practical terms) to the outcome predicted by adherents to one ethical school of thought or another (pp196)

The law is (quite rightly) under unrelenting scrutiny for the ways in which it strives "day by day to solve the real problems of real people" (Birks, 2000:2-3). Bioethics might provide such scrutiny but, in its

<sup>37</sup> I know of socio-legal scholars who already incorporate the methodological insights offered by empirical bioethics, and such cross-fertilisation seems promising.

<sup>38</sup> Although some argue that bioethics should not become too proceduralist and law-like (Sperling 2008).

<sup>39</sup> *Re A (Children) (Conjoined Twins: Medical Treatment)* [2000] 4 All ER 961, 969, *per* Ward LJ.

<sup>40</sup> E.g. the first instance decision (reversed on appeal) in *R (on the application of Burke) v General Medical Council* [2005] 2 WLR 431.

<sup>41</sup> *In re Quinlan* (1976) NJ 355 A 2d 647.

<sup>42</sup> Indeed, in the case of clinical ethics committees, it arguably provided a building for bioethics to occupy.

unofficial sector at least, it is rarely subjected to the same inspection.<sup>43</sup> Law therefore has the benefit, and undoubted burden, of doing ethics work in the real world and, in doing so, it has surely learnt lessons that bioethics should heed. Law's empirical orientation therefore warrants repetition. Law will sometimes appear to get things ethically 'wrong', according to some theory or other. But perhaps law can teach the ethical theorists something too, about the sorts of practical resolutions to which particular moral problems are most – or least – amenable. This notion speaks clearly to the enterprise that is empirical bioethics, which is prefaced, for many, on the idea of working to provide practically oriented normative solutions that work in context.

And, finally, law's lessons need not be incomprehensible to bioethics: law's *phrasing* can be heard. Lei-Kung and Bronislawski were able to communicate and so too are law and bioethics – indeed, they share a common language, of rules, principles, and rights (Freeman, 2008; Sperling, 2008; Miola, 2006). The commonality is perhaps unsurprising, given the prevalence of academic lawyers in the unofficial sector of bioethics (Rothstein, 2009; Sperling, 2008). Given all this, bioethics can – and arguably should – hear law's voice (Huxtable & Ost, 2015).

### Divergence and Distraction

Whilst law therefore can and does offer much to bioethics, the news is not all good. Law also differs from bioethics in ways that mean each can distract, and detract from, the other. First, returning to the previous point, problems of *articulation* do arise. Law's styles and conventions – at least within a strict legal arena – certainly differ from those adopted in bioethics' sectors: lawyers address one another in formal, indirect and cautious (as opposed to clear) terms, and they will conventionally defer to authority (van der Burg, 2010; Sullivan & Reynolds, 1998). Although bioethics invites a degree of deference,<sup>44</sup> its practitioners seemingly prefer the pursuit of clarity and defensibility and, whilst their opinions remain revisable in principle, their exchanges can be very direct indeed.<sup>45</sup>

Here too there are problems not only of style but also of substance. Lei-Kung and Bronislawski each faced the difficulty of translating particular words for their flatmate. In law and bioethics, we find that even common words have uncommon, technical meanings (van der Burg, 2010):<sup>46</sup> for example, pluralistic legal accounts of respect for autonomy do not necessarily correspond with the equally pluralistic accounts writ in bioethics' corpus (e.g. Foster, 2009). Whenever a discipline re-frames an issue in its terms, it risks stripping the presenting problem of "the complex facticity with which it actually presented" (Callahan, 1973:69). Law might be particularly susceptible to this reductionist charge: a complex, fractious issue like assisted dying is swept into a brute legal category and emerges unrecognisable to bioethics (and even the protagonists) as the original dilemma.<sup>47</sup> The resulting problems of translation return us to law's purpose: as Schneider (1994) puts it:

we should remember that the law's calling is to regulate social life, however awkwardly, and its language reflects that purpose (pp22).

We saw earlier that bioethics can share this purpose, but Schneider hints here that bioethics might also be doing and saying more than this; if so, then there may be limits to "the extent to which the language of the law may safely be imported into bioethical discourse and to which bioethical ideas may be effectively translated into law" (Schneider, 1994:22; see also Freeman, 2008; Sperling, 2008; Foster, 2009).

Secondly, and related to law's prose and purpose, law is *adversarial*, particularly where judicial proceedings are concerned. Like legal cases, bioethical dilemmas "revolve around a nexus of competing or conflicting claims" (Sullivan & Reynolds, 1998:610). Law seeks a winner:

<sup>43</sup> Note, however, the furore sparked by Giubilini and Minerva (2013), with their paper 'After-birth abortion: why should the baby live?'

<sup>44</sup> Not only in the formal sector, but also in the unofficial, academic sector (for example, students should show due regard – if not unquestioning respect – for standard texts).

<sup>45</sup> E.g. between Harris and Finnis in Keown (1997).

<sup>46</sup> A discipline might require some technical tools, although it is notable that in each there have been calls to purge unnecessary jargon: e.g. Butt (2001); Callahan (1973); Cowley (2005).

<sup>47</sup> E.g. the English rulings culminating in *R (on the application of Pretty) v DPP* [2002] 1 FLR 268.

“so much of what is taught in law school is about winning: winning the case, winning the arguments, or winning the point” (Sullivan & Reynolds, 1998:620).<sup>48</sup>

Yet, bioethics’ problems “are not black and white, but are often composed of multiple shades of grey” (Mellor & Barclay, 2011:619),<sup>49</sup> in which there might be two competing rights, as opposed to a right and a wrong (Sperling, 2008).

Certainly, law’s decisions are not always monochromatic: it sometimes manages to split the difference between disputing parties or principles (Huxtable, 2012). Yet, law still decides – it *acts* – and this points to a third area of divergence. Law is, as Fuller suggested, action-orientated: law might therefore seek to kill the conflict (van der Burg, 2010), while philosophical bioethics could opt for over-kill, further complicating matters (Callahan, 1973). Schneider hinted that bioethics encompasses more than the rules and action that fixate law; when we pan out, we can indeed see more of bioethics’ diverse landscape, on which the emotions, character, and the virtues also feature. Whether law can adequately talk to or about such matters is, of course, an enduring question (e.g. Slote, 1995; Solum, 2003).

Law’s adequacy is further questioned when we consider its *aspirations*. You will recall that Bronislawski disliked Lei-Kung’s contrivances, while Lei-Kung felt that Bronislawski, the dreamer, got in his way. Law’s rules perform many functions, amongst them setting standards and drawing lines between the permissible and impermissible. The fourth problem for bioethics is that law might draw the line in the wrong place, since it insists on only minimal standards, regarding what *must* be done, while (bio)ethics aspires to what *should* be done (e.g. Sullivan & Reynolds, 1998; Rothstein, 2009; Freeman, 2008; Sperling, 2008; Maclean, 2008). The bioethics journals contain many examples but the English courts’ long-standing reluctance to require (fully) ‘informed’ consent suffices (Maclean, 2008). Even the judges appear uneasy about the moral ramifications of some of their rulings, no matter how apparently sound they are in law.<sup>50</sup>

Perhaps, then, law needs a bioethical bolt-on. “Good ethics committees begin where the law ends” suggests Annas (1991:21), providing just one example of how the disciplines might rightly remain separate, with bioethics (literally) providing added value to the law.<sup>51</sup> But, as we have seen, law does advance or adopt particular moral positions. So what sort of (bio)ethics should we expect to see *in* law? Bioethics’ broadly composed congregation subjects law to a cacophony of critique: consider, for example, the diverse bioethical positions taken on laws governing assisted dying, embryo research and organ transplantation. Law will, inevitably, talk past some of these complainants (Sperling, 2008). So, recalling a famous exchange between Hart (1963) and Devlin (1959), should law express a positive morality, which commands popular support, or should it reflect a more critical morality, such as we might associate with bioethics? (van der Burg, 2010) We saw earlier how law seems to borrow from each sphere, occasionally citing public opinion, and elsewhere referring to the different sectors of bioethics (Miola, 2006 & 2007). Unfortunately, such selections are just that: selective and inconsistent, with law seemingly lacking any robust or transparent methodology for making its moral choices.

Maybe a messy morass of morals is appropriate, if law is only concerned with setting the minimal standards for communal living - which, as we saw, it might achieve by capturing a compromise between values, plural (Huxtable, 2012). But not every bioethicist will agree, perhaps understandably so, once we appreciate that law and bioethics can have very different *audiences*. Law seems often to be targeted at the transgressor, not the utopian. These transgressors will reside in a given jurisdiction, under the dominion of particular laws. The jurisdiction may be wide,<sup>52</sup> but an essential point is that law is thereby relative to a particular place and, indeed, time. Time can even be a problem for law: it might sometimes get there first, but law will often lag behind developments in science and even in morals

<sup>48</sup> Law’s warrior mentality has even led one judge to depict consent not in the bioethical terms of autonomy, but as conferring a “flak jacket” that protects the health professional: *Re W (A Minor) (Medical Treatment: Court’s Jurisdiction)* [1992] 3 WLR 758.

<sup>49</sup> Given such differences, bioethicists might need to proceed cautiously whenever they are called to be expert witnesses in a legal battle: see Sullivan and Reynolds (1998).

<sup>50</sup> E.g. *Airedale NHS Trust v Bland* [1993] 2 WLR 316, 387, *per* Lord Browne-Wilkinson.

<sup>51</sup> Montgomery (2006) fears the growing “de-moralisation” of English medico-legal rulings

<sup>52</sup> Even cross-jurisdictional e.g. in international law, federal law in the USA and the laws of the European Union and European Convention on Human Rights.

(Rothstein, 2009; Sullivan & Reynolds, 1998). Bioethics can be relativistic<sup>53</sup>, and even myopic (Campbell, 2000), but it will also, on occasion, aspire to universality; law, meanwhile, remains tethered to a territory, issuing its edicts to its subjects, under the watchful, questioning and sometimes uncomprehending gaze of bioethics.

### **(Happy) Endings?**

In conclusion, I have suggested that there are numerous contributions that law can make, and has made, to bioethics, which I have described as five P's, which encompass law's purpose, processes, products, practices and phrasing. There is, therefore, much that law has to offer bioethics, particularly insofar as law is inherently empirically-oriented and therefore offers a real world testing ground for particular types of solutions to particular moral problems. Like Bronislaw and Lei-Kung, law and bioethics do manage to communicate with one another more than some might believe (Foster, 2009). This is unsurprising given their close co-existence. Indeed, just as it can be difficult to define law in a way that does not beg moral questions, so too it can be hard to define bioethics without some reference to law. If the differences between law and bioethics are only gradual and contextual, as Van der Burg (2010) indicates, then there may be much that each can learn from the other.

Equally, however, I have argued that the relationship is marred by five A's, which concern law's articulation, angst, action-orientation, (lack of) aspiration and audience. Some of the problems between these flatmates might be attributed to a lack of understanding of what each is and does: bioethics might over-emphasise law's authoritarian or argumentative sides, while law might fail to see that bioethics involves both consensus and controversy (van der Burg, 2010; Miola, 2006). Different authors offer different prescriptions for the various ills that afflict the couple, ranging from separation to the acquisition of new roles (Sperling, 2008; Brownsword, 2008; Wolf, 2004). For my part, I suspect that better appreciation of what each brings to their shared areas of interest provides a good place to start. Neither, it seems, can entirely replace the other (Sperling, 2008); like our flatmates, each can benefit the other and, indeed, the wider communities they inhabit and serve, not least by spotting something that the other might miss. Whether or not bioethics itself is 'a full discipline', the opportunity remains – in Callahan's words – for 'creativity and constant re-definition' (Callahan, 1973). We should, therefore, continue to configure the relationship between law and bioethics, moving it on from its 'haphazard' beginnings (Miola, 2006). Sometimes friends, sometime foes, they may yet become spouses.

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### **References**

- Annas, G. 1991. Ethics committees: From ethical comfort to ethical cover. *Hastings Center Report*, 21: 18-21.
- Arras, J. 2013. 'Theory and bioethics', *The Stanford Encyclopedia of Philosophy*. E.N. Zalta, ed. Available at: <<http://plato.stanford.edu/archives/sum2013/entries/theory-bioethics/>>
- Beauchamp, T. 1991. *Philosophical Ethics: An Introduction to Moral Philosophy*. New York: McGraw Hill.
- Beauchamp T. Childress J. 2013. *Principles of Biomedical Ethics*, 7th edn. Oxford University Press.
- Birks P. 2000. Rights, wrongs, and remedies', *Oxford Journal of Legal Studies*, 20(1):1-37

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<sup>53</sup> See Sheehan's (2016) chapter in this volume for a discussion of the implications of relativism for (empirical) bioethics.



- Brownsword, R. 2008, 'Bioethics: Bridging from morality to law?' in M. Freeman (ed), *Law and Bioethics: Current Legal Issues 2008*, Volume 11. Oxford University Press: pp12-30
- Brownsword, R. 1991. 'Towards a rational law of contract' in T. Wilhelmsson (ed.), *Perspectives of Critical Contract Law*. Aldershot: Dartmouth. pp241-272.
- Butt P, 2001. 'Legalese versus plain language', *Amicus Curiae*, 35:28-32.
- Callahan, D. 1973. 'Bioethics as a discipline'. *The Hastings Center Studies*, 1(1):66-73
- Callahan D. 1996. 'Escaping from legalism: Is it possible?', *Hastings Center Report*, 26(6):34-35.
- Campbell, A. 2000. "'My country tis of thee': The myopia of American bioethics", *Medicine, Health Care and Philosophy*, 3(2):195-198.
- Coggon J, 2010. 'Assisted dying and the context of debate: "Medical law" versus "end-of-life law"', *Medical Law Review*, 18:541-563.
- Cowley C. 2005. 'The dangers of medical ethics', *Journal of Medical Ethics*, 31:739-742.
- Daniels N. Sabin J. 1997. 'Limits to health care: Fair procedures, democratic deliberation and the legitimacy problem for insurers', *Philosophy and Public Affairs*, 26(4):303-350.
- Dawson A. Wilkinson S. 2009. 'Philosophical clinical ethics', *Clinical Ethics*, 4:36-37.
- De Vries M. Van Leeuwen E. 2010. 'Reflective equilibrium and empirical data: Third person moral experiences in empirical medical ethics', *Bioethics*, 24(9):490-498.
- Devlin P. 1959. 'The Enforcement of Morals', *Proceedings of the British Academy*, XLV:129-151
- Foster C. 2009. *Choosing Life, Choosing Death: The Tyranny of Autonomy in Medical Ethics and Law*. Oxford: Hart.
- Foucault M. 1977. *Discipline and Punish: The Birth of the Prison*, trans. Alan Sheridan. New York: Vintage.
- Freeman M 2008. 'Law and bioethics: Constructing the inter-Discipline', in M. Freeman (ed), *Law and Bioethics: Current Legal Issues 2008*, Volume 11. Oxford University Press. pp. 1-11
- Fuller L 1969. *The Morality of Law*, revised ed. New Haven: Yale University Press.
- Genn H, Partington M, Wheeler S. 2006. *Law in the Real World: Improving our Understanding of How Law Works*. Nuffield Foundation. para 16
- Giubilini A. Minerva F. 2013. 'After-birth abortion: why should the baby live?' *Journal of Medical Ethics*, 39: 261-263.
- Hart H. 1953. *Law, Liberty and Morality*. Oxford University Press.
- Hart H. 1965. 'Review: Fuller, *The Morality of Law*', *Harvard Law Review*, 78:1281-1296.
- Hedgecoe A. 2004. 'Critical bioethics: Beyond the social science critique of applied ethics', *Bioethics* 18(2):120-143.
- Huxtable R. 2012. *Law, Ethics and Compromise at the Limits of Life: To Treat or Not to Treat?* London: Routledge.
- Huxtable R. 2007. *Euthanasia, Ethics and the Law: From Conflict to Compromise*. London: Routledge-Cavendish.
- Huxtable R. Ost S. 2015. 'Voices Carry? The Voice of Bioethics in the Courtroom and Voice of Law in Bioethics', in R. Huxtable and R. ter Meulen, *The Voices and Rooms of European Bioethics*. London: Routledge.

- Jonsen A. 1998. *The Birth of Bioethics*. Oxford University Press.
- Keown J. ed. 1997. *Euthanasia Examined: Ethical, Clinical and Legal Perspectives*. Cambridge University Press.
- Maclean A. 2008. 'Magic, myths, and fairy tales: Consent and the relationship between law and ethics', in M. Freeman (ed), *Law and Bioethics: Current Legal Issues*, Volume 11. Oxford University Press. pp11-135,
- McLean S. 2008. 'Clinical ethics committees: A due process wasteland?' *Clinical Ethics*, 3:99-104.
- McLean S. 2007. 'Law, ethics and health care', in R. Ashcroft, A. Dawson, H. Draper and J. McMillan (eds), *Principles of Health Care Ethics*, 2nd edn. Chichester: John Wiley and Sons. pp193-198.
- Meller S. Barclay S. 2011. 'Mediation: An approach to intractable disputes between parents and paediatricians', *Archives of Disease in Childhood*, 96: 619-621.
- Miola J. 2006. 'The interaction of medical law and medical ethics', *Clinical Ethics*, 1(1): 22-25.
- Miola J. 2007. *Medical Ethics and Medical Law: A Symbiotic Relationship*. Oxford: Hart.
- Montgomery J. 2006. 'Law and the demoralisation of medicine', *Legal Studies*, 26(2): 185-210.
- Nuffield Council on Bioethics. 2006. *Critical Care Decisions in Fetal and Neonatal Medicine: Ethical Issues*. London: Nuffield Council on Bioethics. para. 2.2.
- Priault N. 2013. 'The troubled identity of the bioethicist. *Health Care Analysis*, 21(1): 6-19
- Rawls J. 1972. *A Theory of Justice*. Oxford University Press.
- Regan T. 2004. *The Case for Animal Rights*, 2nd edn. Berkeley: University of California Press.
- Reich W. 1995. *Encyclopedia of Bioethics*. Vol. I. New York: Macmillan.
- Riddall, J. 1999. *Jurisprudence*, 2nd edn. Oxford University Press.
- Rothstein M. 2009. 'The role of law in the development of American bioethics', *J Int Bioethique*, 20(4): 73-111.
- Schneider C. 1994. 'Bioethics in the language of the law', *Hastings Center Report*, 24(4): 16-22
- Silber T. 1982. 'Bioethics: An interdisciplinary enterprise', *Journal of Religion and Health*, 21(1):21-28.
- Slote M. 1995. 'Law in virtue ethics', *Law and Philosophy*, 14(1): 91-113
- Solum L. 2003. 'Virtue jurisprudence: A virtue-centered theory of judging', *Metaphilosophy*, 34(1/2): 178-213.
- Sheehan M. 2016. *Metaethics, relativism and empirical bioethics*. **This volume.**
- Stirrat G. 2003. 'How to approach ethical issues: A guide', *The Obstetrician & Gynaecologist*, 5: 214-217.
- Sperling D. 2008. 'Law and bioethics: A rights-based relationship and its troubling implications', in M. Freeman (ed), *Law and Bioethics: Current Legal Issues*, Volume 11. Oxford: Oxford University Press. pp52-78
- Sullivan M. Reynolds D. 1998. 'Where law and bioethics meet ... and where they don't!!', *University of Detroit Mercy Law Review*, 75; 607-620.
- Teel K. 1975. 'The physician's dilemma: A doctor's view: What the law should be', *Baylor Law Review*, 27: 6-9.

van der Burg, W. 2010. 'Law and ethics: The twin disciplines', Erasmus Working Paper Series on Jurisprudence and Socio-Legal Studies No. 10-02. Available at: <<http://ssrn.com/abstract> (no. = 1631720)>, 2.

vanTheil, G. vanDeldan J. 2016. Reflective equilibrium as a normative empirical model: The case of Ashley X. This volume.

Veatch R. Miller F. eds. 2001. 'The internal morality of medicine'. Journal of Medicine and Philosophy, 26(6).

Watkins D. Burton M. eds. 2013. Research Methods in Law. Oxon: Routledge.

Wolf S. 2004. 'Law & bioethics: From values to violence', Journal of Law, Medicine & Ethics, 32: 293-306, 293.

# Embracing Diversity in Empirical Bioethics

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In this chapter we make a positive case for a diversity of approaches to bioethics in general and empirical bioethics in particular. We suggest that there is much to be gained from embracing pluralism, and a certain degree of open-mindedness, in relation to the methodology of bioethics. In broad terms we are arguing for methodological toleration founded on individual and collective reflexivity about aims and methods: bioethics is a broad area, and the diversity of aims which sit within the extensive field of bioethical scholarship call for a variety of methods to be employed. Moreover, we suggest, reflexivity about aims and methods supports the development of new forms of bioethical scholarship. We, of course, accept that there are limits to defensible toleration, but our worry is that conflicts about the nature and scope of bioethics can kick in well before those limits, and are sometimes needless, damaging to the field and insufficiently reflexive about the reasons for methodological differences.

## Interdisciplinary conflict in bioethics

Our focus derives its importance from the nature of bioethics as contested territory. For some time bioethics has been a site for conflict between scholars approaching it from different disciplinary traditions, with disputes between sociologically and philosophically oriented scholars having been particularly heated. We will begin by illustrating these contests by drawing upon some rather stereotypical conceptions of sociology and philosophy. In reality, as we will go on to suggest, the boundaries are less clear-cut and there is considerable heterogeneity within disciplines.

In brief, 'sociological bioethicists' have accused 'philosophical bioethicists' of working at too great a remove from the complex, and historically and culturally constituted, contexts of action to be able to make a practical contribution to ethics. There is now a well-established critique of purely philosophical approaches to bioethics from medical sociologists and others (Bosk 1999; Fox & Swazey, 1984; Hedgecoe, 2004; Hoffmaster, 1992; Ives and Dunn, 2010), which argues that the over-idealised and theoretical nature of philosophical ethics undermines the validity of its claims and reduces its relevance to practice. The motivation for such a critique arises, in part, from the long tradition within social scientific research of engaging with social contexts and for detailed attention to actual circumstances and behaviours. Against this light, a propensity for producing ideal theory and abstract universal principles, and the tendency within mainstream philosophical bioethics of preferring conceptual analysis and theoretical reasoning over empirically informed description and understanding has been seen by some as a significant weakness.

In reply, many philosophers have failed to see the potential relevance of applied social scientific research to ethics. Philosophical bioethicists tend to be sceptical about much of the work done in the name of sociological bioethics, viewing such scholarship as work *about* ethics rather than work *in* ethics. No doubt this has partly been shaped by the longstanding distinction often made between 'normative' questions and 'empirical' questions, which has gone a long way to producing the cultural and methodological divides between philosophy and the social sciences.<sup>54</sup> And more fundamentally, as Borry et al (2006) put it, "the meta-ethical distinction between 'is' and 'ought' created a 'natural' border between the disciplines" (pp54). Within the field of bioethics, this divide has proven remarkably difficult to overcome.

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<sup>54</sup> See also MacMillan's (2016) chapter in this volume.

As a consequence of their disciplinary heritage, philosophers working in the field of bioethics have often seemed reluctant to 'get their hands dirty' with empirical methods, seeing ethics as essentially an abstract and theoretical enterprise primarily concerned with normative reasoning rather than descriptive or explanatory reasoning. Indeed, some go so far as suggesting that, at a fundamental level at least, normative principles must exist independently of any factual claims about the world (e.g. Cohen, 2003). More routinely, philosophical approaches to bioethics often tend to treat empirical data as a raw 'descriptive material', which can be used to feed the proper business of normative and conceptual analysis.

One reason for the abstract and detached nature of philosophical ethics may be the lingering assumption, on the part of some at least, that the proper role of ethics is to produce universal ethical ascriptions, rather than those which apply to particular contexts (albeit there are other philosophical bioethicists who explicitly identify with 'particularist' ethical theories.) This tendency towards abstract generalism can be coupled with a concern that resorting to sociological and/or anthropological accounts of ethics which rest upon descriptions of moral beliefs, values, practices and arrangements brings with it some form of cultural or moral relativism where "there exists no way of criticising or analyzing these values, nor for arguing for what is morally right" (Clouser, 1973:788).<sup>55</sup>

These differences between disciplinary traditions can take a variety of forms, some more serious than others. For instance, it might be that philosophers and social scientists are merely talking at cross-purposes to one another. Here the feeling might be that the work of the other camp may be valuable in its own right, but happens to be irrelevant to one's own purposes and therefore not really worth engaging with. A social scientist may think it important that philosophers analyse the nature of well-being, but be relatively uninterested in the outcome of the inquiry in the abstract terms in which it is presented. Alternatively, a philosopher may appreciate the value of a social scientist investigating the perceptions of the various stakeholders about what count as 'surplus' embryos in the context of fertility treatment whilst regarding this research as irrelevant to their investigation into the moral status of embryos.

A more serious case of divergence can arise if parties become inclined to the view that the other is simply missing the point. Sociologists may feel that abstract and general accounts of the right or the good in bioethics, which are not grounded in concrete circumstances and problems, fail to engage with the central purposes of bioethical scholarship. For example, a social scientist may take issue with a philosopher who fails to say how the ideal model of distributive justice they have outlined may be practically applied to any specific question of resource allocation. Philosophers, by contrast, may feel that descriptions or explanations of social phenomena, however well grounded or rich, just do not address the central question of *what ought to be done*. For instance, while a philosopher may be happy to admit the importance of recognising instances of oppression where they occur within medical practice, she may be aggrieved if the researcher responsible fails to consider whether or not some such oppressive practices can be justified.

Another serious type of cross-disciplinary conflict might be caused by the feeling that some work in bioethics can positively alienate audiences and undermine the potential of bioethics as a disciplinary field. For instance, one can well imagine a social scientist researching programmes for improving organ donation rates feeling exasperated by John Harris's famous *Survival Lottery* (1975), or the policy-maker responsible for negotiating the legal status of abortion clinics being frustrated by Giubilini and Minerva's (2012) argument for post-birth abortion.

To those interested in addressing practical questions within specific contexts, the sort of abstract reasoning and thought experiments found within the philosophical bioethics literature might be seen as lacking moral and political seriousness and as potentially damaging to those seeking practical solutions to bioethical issues. Such feelings of frustration can be substantially mitigated by researchers articulating the aims of their research (Oswald, 2013; Ives & Dunn, 2010). Clarification of purposes is an important step towards managing potential conflict within the field.

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<sup>55</sup> See also Sheehan's (2016) chapter in this volume.

It is against this backdrop of disciplinary conflict that the emergence of empirical bioethics makes sense – it emerges from the ambition to transcend disciplinary divisions by contributing to normative discussions about what ought to happen in a way that is informed by, and sensitive to, ‘real world’ contexts, perspectives and considerations. This conflictual backdrop also enables us to summarise our main argument: sociological and philosophical approaches to bioethics can have different aims and employ different methods and both can make a positive and legitimate contribution to bioethical scholarship. This is not an especially new or challenging argument, but we suggest that it is one that is worth rehearsing from time to time. If a sociologist criticises a philosopher for not doing x, or a philosopher criticises a sociologist for not doing y, one perfectly sensible response is for the accused party to simply say they were not aiming to do x (or y). The philosophical bioethicist can say, for example, “In this piece of work I was not trying to make a practical contribution to ethics; I was making a theoretical contribution”. Likewise the sociologist can say, “In this work I am not making claims about what ought to happen, I am doing something different – e.g. I am trying to understand why certain norms become prominent under certain institutional conditions”. Having different aims is a perfectly good reason for doing different things and for adopting different methods. When something like this is the case – when scholars are operating in parallel on different kinds of projects – it is necessary to understand any tension between them accordingly. Any conflict is not a disagreement about the best way of doing the same thing (x or y, because only one party is attempting x or y respectively). It may, for example, simply be a conflict over resources - perhaps they are competing for a single ethics grant or post - or it may, more substantively, be a disagreement about the relative worthwhileness of different kinds of project. These forms of competition or disagreement may be important but they are not disagreements about ethics methodology.

We would argue that the account of diversity and disagreement between disciplines that we have just offered also applies to more fine-grained forms of conflict in bioethics and empirical bioethics. That is, in order to determine whether an apparent disagreement between approaches is an actual disagreement, and, more specifically, what it is a disagreement about, we first have to ask about the precise aims of different approaches. Much of the time scholars will simply be aiming to do different kinds of things and this will help explain, and in many cases will justify, methodological diversity (see Davies *et al*, 2015). There will also be instances where rival scholars are not operating completely in parallel but are engaged in overlapping projects and are making competing claims about methodology. Here it makes sense to apply effort to the contestation and resulting debates. But we should definitely not rush to assume that any divergence of approach falls into that category. Even where there is direct contestation about the defensibility of different methodologies for similar aims then diversity of practice can still have a role in advancing debates in the field because such disputes are unlikely all to be settled *a priori* i.e. without a degree of ‘trial and error’. In short, diversity is often a good thing because it reflects the breadth of the different aims that can be pursued in bioethics scholarship and because it enables methodological exploration and imagination. Indeed, empirical bioethics appears to be a product of imagination and tolerance within the bioethics community and its success demonstrates the potential advantages delivered by recognising and embracing diversity. In the next section we examine the inherently heterogeneous and multi-faceted nature of ethics and how this lends itself to pluralism.

### **The diversity of aims and methods within ethics**

The question, ‘how ought we to live?’, which is close to the heart of ethics, indicates a dual concern with both understanding and action. Ethics is concerned both with furthering our *understanding* of the nature of moral actions and arrangements and also with the *practical implications* of this understanding.

This dual concern with moral knowledge and moral practice makes ethics relevant to a diverse academic and general audience. Given both the breadth of the subject and the range of those interested in it, researchers often seek to approach ethics on their own terms, cutting it down to suit their agendas and methodological traditions by emphasising certain aspects over others in order to focus on the questions and produce the forms of knowledge that they identify as important.

Within the academy, this tendency for managing the breadth and complexity of ethics is to some degree formalised and amplified through the division of intellectual and administrative labour within the academy: distinctions that are drawn between disciplines are often reinforced by organisational structures, for example, through the creation of distinct academic departments, professional associations and journals. Ethics is an area of significant interest to researchers from philosophy, law, sociology, theology, politics, economics and a wide range of other disciplinary backgrounds, yet the academic structuring of institutions means academics interested in ethics may infrequently exchange perspectives on ethics with those outside their immediate subject area.

It is understandable that many researchers have become selective about the sorts of work they engage with, judging it in terms of its relevance to their own interests. While this sort of framing is useful, it can also produce a narrowing effect that can lead to research not being judged fairly and on its own terms. These divisions reveal something important about the multi-faceted nature of ethics, but at their most extreme such attitudes lead to calls for forms of disciplinary reductionism: attempts to draw boundaries around what is deemed to count as the study of ethics, or at least as worthwhile forms of such study. The tensions between philosophical and sociological versions of bioethics can take this form.

Assuming an academic division of labour, it is easier to make a case for multi-disciplinarity than for inter-disciplinarity. Nothing much rests upon simply creating the space for scholars and researchers to pursue their projects within their preferred disciplinary frameworks. Insofar as these are simply different kinds of projects each illuminating different facets of ethics from different directions then there is little reason not to celebrate a rich field of variety. However, simply advocating breadth and variety is not enough. If we want to see how the facets of ethics might fit together then we need to be ready to support multiple conversations involving, and some collaborations between, people with contrasting perspectives.

We can briefly reflect upon two sets of ideal typical distinctions as a heuristic in order to indicate both the range of ethics scholarship and the kinds of dichotomies that are sometime applied to it: the distinction between enlightenment and engineering aims; and the distinction between prescriptive and descriptive methods. We will first illustrate them with reference to the broad tradition of pure and applied philosophical ethics but also indicate their relevance to social science traditions of work. The point we want to make is that these distinctions cut across both philosophical and social science approaches to ethics and cannot be used to construct a clear division of labour between these broad domains.

In exploring the relationship between philosophy and policy making, Dan Brock (1987) draws a distinction between scholarship that is primarily motivated by a concern for *truth* and scholarship that aims to bring about a particular set of *consequences*. This same distinction has been expressed in terms of a difference between models of ethical research that seek to provide 'enlightenment' and those that seek to help 'engineer' particular sets of outcomes (Cribb, 2010).

The enlightenment model's emphasis on truth might be thought of, for example, as encompassing those approaches to philosophical ethics that seek to produce theoretical *knowledge* of ethical concepts in their ideal form. Here the focus is to provide knowledge of idealized, universal concepts, which apply regardless of any specific time or context. John Rawls's *A Theory of Justice* (1971) provides a celebrated example of philosophical ethics that falls within the enlightenment model: Rawls does not aim to show how such institutions could actually be created in practice and this has been cited as a major line of criticism from some. Part of the basis for this criticism is a frustration that Rawls's work is geared towards developing *knowledge of justice* rather than *action towards justice*. If Rawls's work is to be considered useful for achieving practical change it must be of indirect use, e.g. because it is able to act in an informing or guiding capacity.

By contrast, the aim of those working in the 'engineering' model of ethics is not to uncover abstract knowledge of ethics but to identify ethical problems and suggest ways to bring about change and achieve more ethical outcomes in practice. For instance, in *The Idea of Justice* (2009), Amartya Sen, whilst also working in the broad tradition of philosophical ethics, explicitly contrasts his approach to that of Rawls by describing it as primarily concerned with identifying and correcting manifest injustices

that actually occur in the world. Sen sees approaches such as Rawls's as risking redundancy on the basis that ideal conditions do not exist in the world as we find it.

Ethics scholarship in the social sciences can also be loosely classified as containing enlightenment and engineering components. Many sociologists and anthropologists, for example, are keen to stress the theoretical and truth-oriented nature of their work. Others are keen to stress the practical relevance and action-orientation of their work, and its capacity to help change things in valued directions (e.g. some instances of critical theory, action research or activist scholarship).

It is also possible to distinguish between broadly 'prescriptive' and 'descriptive' methodological orientations. Again, whilst this distinction is not entirely clear-cut, it is a useful one to start from given our current purposes. What we are calling 'prescriptive ethics' involves asserting and defending moral claims. Within philosophical ethics (at least within the analytic as opposed to the continental tradition of philosophy), this typically entails using conceptual analysis and logical reasoning to construct internally coherent normative arguments. This kind of prescriptive ethical analysis involves a degree of abstraction since the construction of such arguments almost always involves concentrating one's analysis on the facts, beliefs and principles which are considered central and ignoring (or abstracting from) the many distracting, everyday details that are not. This abstraction, coupled with a strong emphasis on formal reasoning processes, contributes to the impression that prescriptive ethical analysis is removed from the realities of everyday life. Philosophical ethics is sometimes seen as an essentially idealised exercise concerned with the nature of, and relationship between, abstract and/or hypothetical ideas or concepts. However, a similar characterisation could be applied to those components of social science and social theory that make 'prescriptive' claims and more or less explicitly argue for ethical positions. For example, proponents of critical theory – in Marxist, feminist and other variants – typically defend judgements about 'what should be done' (or, perhaps more typically, about 'what should not be done') with reasoning and methods that frequently operate at high levels of abstraction.<sup>56</sup>

Prescriptive ethics is of value for both enlightenment and engineering purposes. It is of obvious use for those philosophical ethicists with enlightenment aims since the reasoning process provides a way of testing the theories and arguments that produce knowledge of abstract moral concepts. However, the prescriptive method also plays a key role in engineering approaches too, since without the ability to elucidate and defend ethical claims one would lack the basis upon which to challenge unjust or unethical behaviours, practices and circumstances or propose more ethical alternatives.

By contrast one might say, for short, that the descriptive method involves establishing facts of ethical relevance whilst refraining from making normative judgements about these facts. This may be important for ethical analysis in general since ethical issues are often bound up with problems of knowledge, so that reducing knowledge deficits may contribute some way towards solving ethical problems. This is particularly obvious for consequentialism – where if one had perfect knowledge of which actions promoted most happiness (or equivalent) many ethical questions could be resolved – but it applies across a wide spectrum of moral and political thought. The Aristotelian view that the good life for human beings cannot be fully understood without knowing what sort of beings humans are has enjoyed support from numerous authors recently (Appiah, 2008; Sayer, 2011; Smith, 2010). This view suggests that information about the causes of human flourishing and suffering is of such obvious importance to ethical scholarship that the descriptive method should be seen as an inherent part of all ethical scholarship.

Descriptive ethics can also help to reveal sites of ethical concern. This is true of social and political theory (and, of course, many other currents in the social sciences) that shine a light on the ethically significant features of the circumstances, practices and relationships that human beings are

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<sup>56</sup> Some people would want to distinguish between the forms of defence offered by sociologists and those offered by philosophers by saying that the former tend to assume their normative premises whereas philosophers are prepared to (or are often expected to) explicitly outline and defend their normative premises. This may be true in a very general sense but this distinction is easily over-stated: sociologists may make their normative premises explicit, or they may offer a different kind of defence of their normative position, for example by grounding it in commonly held moral intuitions. Moreover, even where philosophers attempt to take their defence of normative claims to a more foundational level there are legitimate questions to ask both about how far their attempts are successful and, more practically, how far the day-to-day work of philosophical bioethicists actually rests on this kind of foundational rigour.



embedded within. For instance, through its examination and critique of relationships of oppression and power in the development of European psychiatric practice, Foucault's *Madness and Civilization* (1988) opens up psychiatry as an important and relatively under-explored site for ethical analysis. In addition to revealing problems worthy of serious attention the sociological and social scientific approaches to ethics help to develop understanding of ethics by interrogating often taken-for-granted norms and practices, and providing new kinds of evidence and new ways of conceiving of familiar evidence.

These two functions of descriptive method, drawing attention to areas of ethical controversy and providing important content for normative reasoning, have lead some to regard those engaged in descriptive ethical analysis as 'handmaidens' for prescriptive ethical scholarship (Haimes, 2002). Clearly in this sense descriptive method carries an important, albeit indirect, role in meeting enlightenment aims. However, we would suggest that the descriptive method can also help with the construction of ethical theory in a direct sense, since observation of circumstances, arrangements and practices has an obviously important role to play in guiding our ideas about ethical practice across a wide range of contexts. Our understanding of ethics, and of ethical practice in particular, is often arrived at through experience and observation, as well as through processes of abstract reasoning. This suggestion reflects a meta-ethical commitment on our part: i.e. we believe that some version of 'ethical naturalism' is true – that a meaningful and defensible ethics can only be articulated in relation to an understanding of the nature of ethical agents and the world in which they find themselves. We will say a little more about this in the next section. On this account descriptive method has an important and direct role to play in meeting enlightenment aims.

The descriptive method also has a vital part to play in achieving more practical engineering aims in ethics since effecting change in unjust or unethical circumstances, practices and arrangements will require knowledge of those circumstances, practices and arrangements. Thus descriptive and prescriptive approaches can be employed, often in combination, to meet both theoretically orientated enlightenment aims and practically oriented engineering aims. It is possible to point to a great deal of general ethics scholarship that works between traditions to combine these different aims and methods (e.g. Appiah, 2008; Glover, 1999 & 2006; Sayer, 2011). Empirical bioethics can be understood as one broad field within this larger set of multi-disciplinary and inter-disciplinary scholarship.

### **Managing pluralism in empirical ethics**

Arguments in favour of recognising ethics as an inherently pluralistic subject that accommodates a diverse range of aims and methods need to be considered against concerns about ethics becoming overly diluted. For example, Clouser (1973) warns of the risks of an overly inclusive definition of ethics, arguing that if ethics is to avoid being rendered "meaningless in virtue of its sheer generality" it must be "trimmed down to fighting weight" (pp787). Certainly there is a need to make sure that any piece of ethical scholarship does not lose its focus by attempting to be all things to all people. However, we suggest that much of this danger can be averted by paying closer attention to the aims of ethical scholarship, and on how methods support aims, on a case-by-case basis.

The encouragement of much greater reflexivity about aims and methods within a broadly defined family of empirical bioethics could enable a better recognition and acceptance of the inherent diversity in forms of ethical scholarship. More importantly, it could do so without forcing unnecessary and unhelpful 'closure' on the discipline through unwarranted reductionism; or by over-stating the degree of distance between, or independence between, every strand of ethical scholarship.

We suggest that the notion of methodological purity in ethics is basically misguided. As we have suggested enlightenment and engineering aims, and prescriptive and descriptive methods, all interpenetrate one another. For example, practically oriented ethical scholarship, including scholarship that predominantly employs descriptive methods to achieve some practical change will make at least an implicit appeal to normative principles.<sup>57</sup> More controversially, others claim that

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<sup>57</sup> See, for example, the *guiding* function of ideal theory in Ashcroft (2008) and Robeyns (2008).

certain instances of descriptive ethics are inherently normative. For instance, Sayer (2011) suggests that it is more accurate to describe the holocaust as an event in which 'millions were murdered' than it would be to say that 'millions were killed'. In this instance, Sayer argues that accurate description requires the use of normative concepts and that using the more neutral term of 'killing' would be to mis-describe it in an important sense. This echoes influential arguments advanced within philosophy against certain forms of rationalistic ethical theory and the importance of 'thick concepts' in ethics (e.g. Williams, 1985).<sup>58</sup>

Indeed, the construction of ideal knowledge about even the most abstract moral concepts seems to require at least some minimal knowledge of the world to which these concepts apply. As Doris and Stich (2005) put it "answers to important ethical questions require - and have very often presupposed - answers to empirical questions" (pp115: see also Appiah, 2008). For example, any moral theory that is entirely oblivious to naturalistic facts about human mortality or the practical realities of human flourishing and suffering will be deeply inadequate in an important sense. Ethics concerns itself with practical questions about what people ought to do, and since everything that is done is done in practice some reference to the real world of practice seems necessary and inescapable for ethical scholarship.

We would like to stress that this argument for diversity does not amount to the claim that individual ethicists are not justified in reducing the aims and focus of their research, nor does it imply that they must seek to expand their methodological repertoire to embrace alternative methods of ethical analysis: no doubt such a claim would be as unhelpful as it is unrealistic. We see nothing wrong with working within the narrow parameters of a particular genre of ethics, but, where this applies, it is helpful to see that this is what one is doing. However recognising diversity and potential complementarity creates the conditions for developing innovative forms of ethical scholarship.

Empirical bioethics falls into this category. In 2006, Borry et al. described evidence of what they termed an "empirical turn" in medical ethics and bioethics, citing an increase in the publication of research in which empirical research techniques are used. They cite work such as Molewijk et al.'s (2003) call for an "integrated empirical ethics" in which the processes of factual description and normative prescription are explicitly treated as mutually dependent, interwoven strands which influence one another at each stage of the research process. Approaches to ethics of this sort often rest on the problematisation of the distinction between facts and values, a claim that will no doubt be controversial for some, although there are a growing number who seem ready to make such a problematising move (Appiah, 2008; Blackburn, 1998; Doris & Stich, 2005; Gibbard, 1990; Harman, 1999; Putnam, 2004). To use Hilary Putnam's terminology, empirical approaches to ethics tend to view facts and values as separate but 'entangled' entities that must be considered in tandem.<sup>59</sup>

The methodological implications of such a view have been explored by a variety of authors (Borry et al., 2008; MacMillan & Hope, 2008; Widdershoven et al., 2009; Widdershoven & van der Scheer, 2008) with a central feature of these approaches being a desire to fuse together normative and descriptive techniques in an on-going cyclical process which leads to the advancement of both enlightenment and engineering aims. Method in empirical bioethics includes treating practice as a source of knowledge. For example, Molewijk et al. (2003) discuss how an empirical bioethics approach can be useful in the context of understanding the moral dimensions of clinical decision-making in medicine.

This understanding allows the integrated model of empirical ethics to capture the complexities of clinical decision-making in a way that more standard approaches to bioethics do not. It rests on the insight that clinical decision-making is an ethical as well as a technical task which demands consideration of the values attached to courses of action as well as to the scientific facts, and treats these two strands as mutually intertwined. Molewijk et al.'s integrated empirical ethical approach calls for strong co-operation between bioethicists and scientists so that value judgements and technical scientific assessments can be made together and in light of one another.

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<sup>58</sup> See MacMillan's (2016) chapter, in this volume, for discussion of how the notion of 'thick concepts' impacts upon the fact/value distinction.

<sup>59</sup> See MacMillan's (2016) chapter, in this volume, for a more detailed exposition of this idea.

It is important to note that both ethical and scientific elements of decision-making are subject to revision during this process. For example, Widdershoven and Van der Scheer's (2008) approach to empirical ethics, described as "pragmatic hermeneutics", is critical of attempts which seek to frame ethical issues in terms of strictly defined principles based on abstract reasoning. Just as biomedical decision-making must be evaluated with reference to the moral dimensions of the situation, pragmatic hermeneutics suggests that ethical evaluation ought to be addressed pragmatically with reference to the particular biomedical (and psycho-social) context. Since the aim of the analysis is to provide a solid basis for moral action in particular cases and not (at least primarily) to produce general rules and principles for action, Widdershoven and Van der Scheer suggest ethical analysis should be sensitive to the complex concrete circumstances in which the subject of analysis is based in a way that requires a degree of empirically derived knowledge of these circumstances. (Also see the Landeweer, Molewijk and Widdershoven chapter in this text.)

There is a danger that reductionist perspectives will choke off the potential of an integrated empirical ethics. We would like to see ethicists broaden their view of bioethics in a way that creates space for such innovative approaches to grow and develop. This demands reflexivity about the aims and methods of ethical scholarship which, we suggest, can support a sense of security for scholars about their own work as well as a sense of toleration for the work of others.

### **What qualifies as empirical bioethics?**

Given the broad conception of ethics, including bioethics, scholarship we have endorsed thus far we want to advocate for a relatively elastic conception of empirical bioethics that admits a variety of disciplinary communities. In particular we want to encourage the notion that people with histories and identities rooted in a range of disciplines, including not only philosophy but also sociology and other social sciences, can qualify as working in empirical bioethics. Developing the line we have taken to this point we would suggest that one important condition for work to qualify as empirical bioethics is that it pays attention to (or at least contains resources to respond to questions about) the rigour of its claims. For purely descriptive bioethics this will principally mean its empirical claims, but for most work it will include both its empirical and normative claims.<sup>60</sup> This is a deliberately vague boundary. In particular we do not have a specific conception of rigour in mind. What counts as rigour will vary according to the relevant epistemic community and disciplinary framework, and, of course, according to the aims and focus of the specific research project under consideration. This degree of open-endedness is designed to encourage a starting frame of toleration between communities and to encourage inter-disciplinary dialogue. Even on the basis of this very elastic conception then a lot of work is excluded from empirical bioethics – most obviously work in theoretical bioethics that does not use primary or secondary empirical data and makes no significant empirical claims. But it also will exclude an indeterminate amount of, but a good deal of, work where there is little attention to the relevant kinds of rigour and few or no discernible resources for others – even given interpretive charity – to analyse the bases of the empirical and normative claims being made or relied upon. Of course we are not suggesting that just because some conception of rigour is explicitly or implicitly deployed that others should automatically recognise it and accept that such work is of good quality or even sound. All we are suggesting is that such work will be over the threshold for being taken seriously as part of the extended family of empirical bioethics, and that any criticism or dismissal of such scholarship will have to be based upon a closer engagement with the work and the standards being applied rather than simply because it falls into a particular genre.

Leaving aside purely descriptive or essentially non-empirical work for now, the challenges for people coming to empirical bioethics from philosophy or social science backgrounds will be slightly different. Broadly speaking, 'philosophical bioethicists' will have to find ways of (or be open to ways of) accounting for empirical rigour in their work, and 'social science bioethicists' will have to find ways of (or be open to ways of) accounting for their (more or less explicit) normative claims. We will say a little

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<sup>60</sup> Whether the phrase empirical bioethics should be used to embrace work that is purely descriptive is a reasonable question. We have no strong feelings on the matter and see it as simply a matter of specification – there are reasons that could be advanced in both directions. Generally we incline to more expansive and 'welcoming' usages of the term, although, of course, it is important to be clear in what sense it is being used in different instances.

more about these challenges, but before doing so we should lodge another reminder that this distinction between 'philosophical' and 'social science' work is far from straightforward –the two already overlap considerably *before* any conscious attempt to bring them together in empirical bioethics or any other form of inter-disciplinarity (something which we will expand on as we continue).

It might be assumed by some that it is easier for philosophical bioethicists to 'add in' a concern for empirical rigour into their work than it is for social scientists to 'add in' a concern for normative rigour, perhaps owing to ideas about the relative accessibility and specialisation of each skill-set. We would recommend scepticism about this assumption (as well as about the idea of the process being simply 'additive'). Indeed, we would suggest – in a slightly provocative spirit, and with the clear risk of exaggeration - that a better way of characterising the situation is that philosophical bioethicists can learn about the philosophy and methodology of empirical work and about normative reasoning from social scientists (as well as, as is more often assumed, vice versa). The social sciences contain very many rich traditions of work, many of which are highly reflexive about either or both epistemological and value claims. Most notably expertise relating to empirical rigour has its locus within debates about research methodology and epistemology, and whilst these are fundamentally philosophical (as well as operational) questions, these questions are most deeply embedded, rehearsed and contested within the large family of social science disciplines. This is only one part of the already existing and considerable inter-penetration of philosophy and social sciences.

The case relating to normative reasoning is analogous, although less clear-cut. There are important currents of normative reasoning in social and political theory, which are embedded in both philosophical and social science circles. This applies most obviously to normative work in the continental tradition of philosophy, which has directly shaped critical and post-structuralist currents in a wide range of empirical (as well as theoretical) social science. Another, related, instance of this kind of long-standing cross-fertilisation, which has had a substantial direct effect in bioethics, is work across feminist philosophy and social science. Indeed, if anything, it is work in mainstream analytical philosophical ethics which is anomalous and which has been less frequently embedded within social science research (there are exceptions e.g. Sen's work on 'capabilities' arose within, and has been widely applied to, economics and development studies).

From the standpoint of analytical philosophical ethics the weak point of the forms of normative reasoning embedded in critical social science work will arise at what we have specified as the crucial threshold (for inclusion in empirical bioethics), namely the capacity of this work to provide an account of normative rigour. Part of the problem here is that much of the work that is done in critical and post-structuralist social science, for example, advances ethical and political positions and arguments implicitly rather than explicitly.<sup>61</sup> Furthermore it is intrinsic to much of this work (especially the post-structuralist variants) to be sceptical about the possibility of positively establishing and defending ethical and political claims. In the most general terms this scepticism reflects a deep-seated worry that claims to knowledge are inevitably bound up with social power and invariably (re)produce forms of exclusion and oppression (and these kinds of issues are discussed further in Jackie Leach Scully's (2016) chapter in this volume).

Nonetheless we would suggest that even though this work has a tendency to resist normative scrutiny there are some genre-specific conceptions of quality that can be discerned and applied in this context. Translating this into the language of rigour may be somewhat awkward and reductionist but, for example and in crude terms, good quality work embodying ideology critique or deconstruction, will disrupt taken-for-granted readings, foster distrust about what the reader may previously have seen as unproblematic, normal, natural or neutral, and indicate new possibilities for understanding phenomena; including illuminating the way in which they arise through binaries, hierarchies and circuits of power that can be both uncovered and interrogated. As with debates about empirical methodology, those who want to critically examine and question the fundamental models and arguments underpinning this work can engage with a substantial body of work in (continental) philosophy, including Heideggerian, Frankfurt School, Foucauldian and more recent scholarship. As a result we take the view that at least some examples of critical social science work ought to qualify as

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<sup>61</sup> In this specific respect there are some parallels with the nature of argument in analytic philosophy, which is for the most part simply *done* rather than methodologically *discussed*.

empirical bioethics. This work, we would argue, should certainly be included in family disputes about what counts as good quality empirical bioethics, rather than simply be excluded from the family. We say this because we believe the kind of normative reasoning associated with these currents of work has a valuable contribution to make to empirical bioethics. In practical terms it means that when empirical bioethicists attend to specific contexts (e.g. specific institutional policies surrounding informed consent; or the enactment of a population screening intervention) they should not only be paying attention to the social construction<sup>62</sup> of the practices and policies they are studying, but they should be mindful of the value and ethical categories that are both embedded in the examples and in their own analysis of it. Do some of these practices and policies, or their own accounts, have gendered (or 'raced' or 'classed') assumptions built into them? Do the categories of analysis, which aspire towards neutrality or some positive conception of justice, actually serve to foster specific economic interests or 'neo-liberal' ideology more generally?

It is these kinds of concerns that make the sociological critique of mainstream bioethics – including, for example, the ideological baggage of principlism - productive. Although there are clear tensions between these more sociological ways of 'doing' ethics and the more mainstream philosophical approaches to applied ethics, there are also considerable parallels and complementarities. For example, analogous criticisms of the limitations of principlism are routine within philosophical bioethics. And there are examples of analogous work in applied philosophical ethics that subvert dominant assumptions about ethical categories, and draw upon social and political theory (e.g. communitarian debates) – for instance, in the growing field of public health ethics. In other words, there is much common ground around which to build an inter-disciplinary conversation. Here, and more generally, we would argue that it is better to see the underlying tensions between disciplinary traditions as generative of productive dialogue within empirical bioethics rather than as a reason for drawing firm boundaries between different types of work.

In this section we have concentrated on one (albeit broad) area of social science that has a clear normative agenda – arguing that bioethics related work informed by these approaches should be included within the family of empirical bioethics. However similar arguments can be advanced for a number of other areas including, for example, some work in phenomenologically inspired qualitative social research and even some quantitative work, such as that in the political arithmetic tradition.

## Conclusion

In summary, this chapter presents an argument for recognising and embracing diversity of aims and methods within ethics in general and empirical bioethics in particular. In the face of historic and on-going tension between those approaching bioethics from distinct disciplinary traditions, we suggest that bioethics is an inherently broad field which is not only able to accommodate a plurality of approaches, but is also open to innovative forms of collaboration between approaches. We suggest that reflexivity about aims and methods, toleration of difference, interdisciplinary communication and charity of interpretation will be important ingredients to developing genuinely interdisciplinary forms of ethics scholarship. As long as the result takes seriously standards of, and contestations about, rigour and does not otherwise shut down alternative forms of scholarship, we suggest that such diversity ought to be welcomed.

## References

- Appiah, K.A. 2008. *Experiments in Ethics*. Harvard University Press
- Ashcroft, R. 2008. 'Fair Process and the Redundancy of Bioethics: A Polemic', *Public Health Ethics* 1(1): 3-9

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<sup>62</sup> We do not wish to imply any form of philosophical idealism by this term.

- Blackburn, S. 1998. *Ruling Passions: A Theory of Practical Reasoning*. Oxford University Press
- Bosk, C. 1999. 'Professional Ethicist Available: Logical, Secular, Friendly', *Daedalus* 128, (4): 47-6
- Borry, P., Schotsmans, P. and Dierickx, K. 2006. 'Empirical Research in Bioethical Journals: A Quantitative Analysis'. *Journal of Medical Ethics* 32: 240-5
- Borry, P., Schotsmans, P. and Dierickx, K. 2008. 'The Origin and Emergence of Empirical Ethics', in Widdershoven, McMillan, Hope, Scheer Vd, (eds.) *Empirical Ethics in Psychiatry*, Oxford University Press, pp. 38-51
- Brock, D. 1987. 'Truth or Consequences: The Role of Philosophers in Policy-Making', *Ethics* 97(4): 786-91
- Clouser, K. 1973. 'Some Things Medical Ethics Is Not', *Journal of the American Medical Association* 223(7): 787-9
- Cohen, G. 2003. 'Facts and Principles', *Philosophy and Public Affairs* 31(3): 211-45
- Cribb, A. 2010. 'Translational ethics? The Theory Practice Gap in Medical Ethics', *Journal of Medical Ethics* 36: 207-10
- Davies, R., Ives, J. and Dunn, M. 2015. 'A Systematic Review of Empirical Bioethics Methodologies', *BMC Medical Ethics*. Available online: DOI 10.1186/s12910-015-0010-3
- Doris, J. and Stich, S. 2005. 'As a Matter of Fact: Empirical Perspectives on Ethics', in Jackson and Smith (eds) *The Oxford Handbook of Contemporary Philosophy*, Oxford University Press, pp 114-152
- Foucault, M. 1988. *Madness and Civilization*. New York: Vintage Books
- Fox, R. and Swazey, JP. 1984. 'Medical Morality is not Bioethics - Medical Ethics in China and the United States', *Perspectives in Biology and Medicine* 27(3): 336-60
- Giubilini, A. and Minerva, F. 2012. 'After-birth Abortion: Why Should the Baby Live?' *Journal of Medical Ethics*. Available online: doi:10.1136/medethics-2011-100411
- Gibbard, A. 1990. *Wise Choices, Apt Feelings: A Theory of Normative Judgment*. Harvard University Press
- Glover, J. 1999. *Humanity: A Moral History of the Twentieth Century*. London: Random House
- Glover, J. 2006. *Choosing Children: The Ethical Dilemmas of Genetic Intervention*. Oxford: Clarendon Press
- Haimes, E. 2002. 'What Can the Social Sciences Contribute to the Study of Ethics? Theoretical, Empirical and Substantive Considerations', *Bioethics* 16(2): 89-113
- Harman, G. 1999. 'Moral Philosophy Meets Social Psychology: Virtue Ethics and the Fundamental Attribution Error', *Proceedings of the Aristotelian Society* 99: 315-31.
- Harris, J. 1975. 'The Survival Lottery', *Philosophy* 50: 81-87
- Hedgecoe, A. 2004. 'Critical Bioethics: Beyond the Social Science Critique of Applied Ethics', *Bioethics* 18(2):1 20-43
- Hoffmaster, B. 1992. 'Can Ethnography Save the Life of Medical Ethics?', *Social Science and Medicine* 35(12): 1421-1431
- Ives, J. and Dunn, M. 2010. 'Who's Arguing? A Call for Reflexivity in Bioethics', *Bioethics* 24(5): 256-265.
- Landeweer E, Molewijk B, Widdershoven G (2016) Moral improvement through interactive research: An example of dialogical empirical ethics. **This volume**

- Leach Scully J. 2016. Feminist Empirical Bioethics. [This volume.](#)
- McMillan, J. and Hope, T. 2008. 'The Possibility of Empirical Psychiatric Ethics', in Widdershoven, McMillan, Hope, Scheer Vd, (eds.) *Empirical Ethics in Psychiatry*, Oxford University Press, pp. 9-23
- Molewijk, A., Stiggelbout, A., Otten, W., Dupuis, H., and Kievit, J. 2003. 'Implicit Normativity in Evidence-Based Medicine: A Plea for Integrated Empirical Ethics Research', *Health Care Analysis* 11(1): 69-92
- Oswald, M. 2013. 'Should Policy Ethics Come in Two Colours: Green or White?', *Journal of Medical Ethics* 39(5): 312-5
- Putnam, H. 2004. *The Collapse of the Fact Value Dichotomy and Other Essays*, Havard University Press
- Rawls, J. 1971. *A Theory of Justice*, Havard University Press
- Robeyns, I. 2008. 'Ideal Theory in Theory and Practice', *Social Theory and Practice* 37(3): 341-362
- Sayer, A. 2011. *Why Things Matter to People*, Cambridge University Press
- Sen, A. 2009. *The Idea of Justice*, London: Penguin Books
- Smith, C. 2010. *What Is a Person? Rethinking Humanity, Social Life, and the Moral Good from the Person Up*, University of Chicago Press
- Widdershoven G., Abma, T. and Molewijk, B. 2009. 'Empirical Ethics as Dialogical Practice', *Bioethics* 23(4): 236-248
- Widdershoven, G. and Scheer LVd. 2008. 'Theory and methodology of empirical ethics: a pragmatic hermeneutic perspective' in Widdershoven, McMillan, Hope, Scheer Vd, (eds.) *Empirical Ethics in Psychiatry*, Oxford University Press, pp. 23-37
- Williams, B. 2006. *Ethics and the Limits of Philosophy*. Abingdon: Routledge

## Section 2:

# Practical perspectives



# Practical perspectives: An Introduction

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Jonathan Ives  
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The development of empirical bioethics has involved serious engagement with questions of methodology and method. Those who have written widely about it have been largely concerned with the way in which social scientific inquiry and ethical inquiry can be brought together in a research setting in very practical ways. They do this, as we discussed in the preface, in order to make practically relevant normative claims, reflecting a more general concern amongst empirical bioethicists about the ways in which bioethics is practiced as a research enterprise. In this editorial, then, we shift our attention away from the central theoretical debates to methodological questions, focusing on the central issue of how empirical bioethics research should be conducted. Importantly, our shift away from theoretical issues does not imply that we depart entirely from these considerations. Indeed, as shall be seen, the ways in which empirical bioethicists articulate methodological approaches to conduct research of this type is critically dependent on the theoretical commitments they endorse.

The core integrative approach that defines empirical bioethics inquiry raises a number of immediate methodological questions about how this integration ought to take place in ways that enable the full potential of both the social scientific and ethical components of the research to be maximised. Such integration, we will go on to say, presupposes the need for novelty in methodological design; good empirical bioethics research requires more than the combining of empirical and ethical phases of research activity if this approach is going to be defensible.

The integration challenge has not stopped bioethicists from putting forward a wide variety of methodologies that lay out blueprints for how research of this type should be designed. A recent systematic review of empirical bioethics methodologies reveals 32 separate methodological approaches presented in the bioethics literature (Davies et al, 2015). This review also makes a number of additional observations about these methodologies that are worthy of considering at length.

First, the authors of the systematic review claim that this typology of methodologies in empirical bioethics can be grouped as either 'dialogical' or 'consultative' in character, representing two poles of methodological orientation on which the majority of the methodologies identified can be situated. Dialogical methodologies are those in which the researchers design a study in such a way that they are able to establish a dialogue with their participants. Through this dialogue, the researchers co-develop understandings of, and solutions to, the morally significant/challenging dimensions of practice, conducting their analysis and drawing their normative conclusions together (in a variety of possible ways). In contrast, consultative methodologies are those in which the researchers and the participants occupy discrete and different roles in the research activity. Here, the researchers act as external 'thinkers' or analysts, gathering empirical data, analysing this data, and then conducting a separate and/or additional ethical analysis to draw normative conclusions independently of the data collection process.

This categorisation of the different methodological approaches that have been developed to undertake empirical bioethics research is useful because it allows researchers to recognise the different ways in which a normative conclusion can be reached, and how it can be justified. Immediately, therefore, we can see that methodological reflection of this kind returns us to more foundational questions about the form of practical ethical claims, and how such claims can be justified. Indeed, the second important observation emerging out of this systematic review is the way in which different methodological approaches take different positions on the question of normative justification.

Davies et al. (2015) argue that these methodologies also differ in terms of how they seek to answer three central epistemological questions relevant to the integration of empirical and ethical inquiry. The first question is how a normative conclusion can be justified, with the various methodologies identified

differentiating themselves in terms of whether they see justification here as a matter of consensus-building or as a matter of appeal to coherence. Broadly speaking, dialogical methodologies are more likely to justify a normative claim that is borne out of some kind of consensus amongst all of those involved in the research activity, and consultative methodologies are more likely to justify the conclusions they draw by reference to coherence. As Davies et al put it, “[a] research method that appeals to consensus to justify a normative conclusion finds moral authority in agreement of some kind”, and “[c]onversely, a research method that appeals to coherence finds moral authority... in rationality and consistency” (pp9). This kind of methodological consideration connects to questions about the nature of normativity in ethics, and raises issues that both McMillan and Sheehan dissect in Section 1 above. In McMillan’s articulation of the concept, normativity in empirical bioethics requires robust ethical argumentation that is more closely aligned to a coherence - rather than consensus - orientated approach to moral justification. This is not to deny, however, that those empirical bioethicists who endorse consensus approaches cannot offer their own substantive accounts of normative justification that is premised on the value of, and need for, social processes in articulating and strengthening moral claims.

The second epistemological question concerns the analytic process through which the conclusion is reached. The different methodologies identified accord different priorities to the role of:

- i) the researcher or analyst who makes central judgements that give form to the normative conclusion;
- ii) the theory, and the consistent development and application of theory, in articulating the normative conclusion, or;
- iii) the stakeholders in the research who come together in a group process to formulate the normative conclusion.

As outlined above, consultative methodologies tend to prioritise the central role of the researchers themselves in conducting analysis and making judgements as part of the research activity. Other consultative methodologies will be theory-driven, where the researchers endorse particular theoretical commitments prior to the onset of the research, with the analysis focusing on specifying how these commitments ought to be applied to a practical ethical problem in light of the relevant views and experiences of the consulted individuals. In contrast, dialogical methodologies are more likely to prioritise the stakeholders in the research; connecting a range of voices in order to link relevant practical experiences such that a normative conclusion is formulated through specific facilitative, deliberative, or consensus building processes.

The third epistemological question concerns the kind of normative conclusion that an empirical bioethics research project aims to draw. This conclusion can be more or less generalisable, depending on how the analytic process has been formulated. Methodologies that prioritise the thinker or the theory are more likely to aim for generalisable conclusions that can extend beyond the practical context in which the empirical work has been conducted. The corollary of this is that researchers operating with these methodologies will need to consider how their generalisable conclusions can be expressed in terms that are meaningful to, and engaging for, context-bound actors, in a way that meets what we called ‘the pragmatic condition’ in the Preface. Those approaches that are oriented towards the involvement of a specific group of stakeholders, or that strive to justify a conclusion by reference to consensus, may be focused on articulating action-guiding recommendations that are limited to the domain of practice in which these stakeholders are situated, or in which consensus is built. This kind of methodological consideration relates closely to the points raised in Section 1 by Sheehan about moral relativism; and those who defend a more ‘local’, consensus-building and stakeholder-orientated approach to empirical bioethics methodology will need to attend carefully to the ways in which the conclusions they draw attend to the objections that Sheehan poses above.

## **Justification and Methodological Design**

For this section we have selected a range of empirical bioethics methodologies that span the different approaches identified in this systematic review, and which take different positions in relation to the three epistemological questions laid out above. These four methodologies are, we believe, broadly representative of the methodological field of empirical bioethics in its current form. In this section of the book we are moving on from foundational questions of justification that give shape to the

conceptual and disciplinary disagreements discussed in Part 1. However, our contention is that one cannot make sense of distinctive methodological approaches without careful consideration of the different philosophical and empirical commitments that empirical bioethics researchers endorse – implicitly or explicitly – in the ways in which they design their research studies. It is for this reason that we invited the authors of the first four chapters in Part 2 to articulate their methodologies alongside detailed justifications of the approaches that they endorse and defend. Whilst these four methodological frameworks represent very different approaches to doing empirical bioethics, we must reiterate that they are by no means the only accounts available. Recently published work on, for example, symbiotic empirical ethics (Frith, 2010), reflexive balancing (Ives, 2015), grounded moral analysis, moral participation, moral conversation (Dunn et al., 2012), and inter-ethics (Abma et al, 2009 & 2010) could all have been showcased below. In this volume we have selected diverging methodological accounts that endorse different justificatory strategies and associated methodological requirements; and our selection strategy is based on showcasing a variety of core ideas, rather than us, as editors, endorsing any one particular set of approaches over others.

#### **Four methodological approaches**

In Chapter 7, Landeweer, Molewijk & Widdershoven outline a methodological approach for EB that they refer to as ‘dialogical empirical ethics’. This methodology represents the culmination of many years of thinking about the central relevance of hermeneutic philosophy for empirical bioethics research (Widdershoven, 2001; Molewijk et al, 2004; Abma et al, 2009; Widdershoven et al, 2009a & 2009b; Landeweer et al, 2011; Voskes et al, 2013), and seeks to produce moral learning and direct improvement to practice by involving stakeholders in a process of reflection and dialogue on moral issues in practice. It is a methodology that Landeweer et al. have developed through combining two cross-disciplinary paradigms of ethical understanding and empirical inquiry: Gadamerian hermeneutic philosophy and responsive evaluation. The former philosophical approach presupposes that moral understanding and ethical action is forged through dialogical exchanges between individuals who come to understand and shape each other’s ‘dynamic horizon’ in communicative exchange. The latter empirical approach embodies the view that research participants are partners in inquiry and change, co-directing how the research takes place and how its conclusions are drawn. Using the example of research into the ethics of coercion in mental health practice, Landeweer et al. show how novel moral solutions to reduce inappropriate coercive measures was dependent on the facilitation and stimulation of dialogue between nursing teams, enabling both the research to take place – and its outcomes to be implemented – in the specific practice contexts in which these individuals work.

In Chapter 8, van Thiel & van Delden provide a detailed account of ‘normative-empirical reflective equilibrium’ (NE-RE) as a methodology for empirical bioethics. In contrast to the dialogical approach articulated by Landeweer et al., NE-RE falls firmly within the consultative set of approaches, drawing heavily on the Rawlsian account of reflective equilibrium to endorse the view that moral intuitions, moral principles, morally relevant facts, and background theories should all be brought together, in a coherent fashion, in order to provide morally defensible arguments to practical ethical problems. Van Thiel & van Delden defend the role that moral intuitions can play in practical bioethical analysis, arguing against the view that incorporating intuitions is to render ethical analysis overtly subjective or erroneous. By emphasising the importance of incorporating intuitions that go beyond the personal insights of the researcher, van Thiel & van Delden defend the robustness of their ethical analysis and stress the value of obtaining unexpected insights, relevant descriptions of experience, and interpretation of moral considerations from a number of different angles. The authors also defend the use of coherence in their methodological approach, arguing against the objection that it is uncertain how much coherence is needed for reflective equilibrium to be reached. Drawing on an empirical analysis of the content of internet message boards, comprising comments on the appropriateness of growth attenuation surgery for a young girl with developmental disabilities, van Thiel & van Delden reveal a wide range of moral intuitions about how the case ought to have been resolved. They incorporate analytic techniques designed to reveal ‘strong’ and ‘weak’ positive and negative inference relations between the intuitions that they systematically analysed and the relevant moral principles they identify (together with the moral theoretical considerations that underpin these principles) in order to make progress in their ethical analysis.

In Chapter 9, Kim outlines a different methodological approach developed out of the political philosophy of deliberative democracy. This is an approach to governance in a liberal democratic

society that demands the state puts in place mechanisms for governance that enable it to outline, and promote dialogue around, the reasons it gives to its citizens for the policy decisions it makes. Further, it must do this in ways that are accessible to, and can be challenged by, these individuals in the public sphere (Gutmann & Thompson, 2004). For Kim, a deliberative democratic approach within politics is the natural bedfellow to bioethical reasoning around decisions that concern public-policy making. The idea that “we could attempt to resolve the conflict by promoting a deliberation among citizens during which an attempt is made to find a common perspective” (pp??) is one that appears to be intuitively appealing, and Kim makes clear that such involvement in public policy-making is preferable, in our current political landscape, to deferring such decision-making to expert panels, commissions, or special interest groups. This methodological approach, as Kim acknowledges, poses a number of difficulties. One such difficulty is in specifying the methodological parameters for high quality deliberative exchange; ensuring that polarised views are managed in such a way that progress can be made in trying to formulate what Kim refers to as a ‘common good’ based policy recommendation. A second difficulty in adapting deliberative democracy for empirical bioethics is to articulate precisely how to reach a ‘common perspective’, or the ‘common good’, and what constitutes the justificatory force of this perspective. In Kim’s discussions of a deliberative democratic approach to the formulation of a policy for the recruitment of adults with dementia in clinical research, it is the focus on the need to develop an ethically defensible policy that applies to members of society broadly that justifies the attempt to find a consensus viewpoint within a piece of empirical bioethics research. This justification would not extend to bioethical issues that do not have a policy dimension to them (for example, where the aim of a piece of research is to shape professional practice in a small-scale context). Kim argues however, that it is the best way to justify practical ethical conclusions around contemporary moral disagreement in societies that endorse democratic modes of decision-making, and when the policy to be introduced necessarily requires the trading off of competing goods or values.

In Chapter 10, Scully outlines a comprehensive feminist approach to empirical bioethics, developing and integrating complementary strands of analysis in feminist philosophy and feminist social science. In Scully’s account of feminist bioethics, the starting concern is that ways of doing bioethics, from conducting ethical analyses to identifying morally salient features of a given practice, are fundamentally gendered, and that this gendered dimension to practical ethics functions to contribute to oppressive practices – both in bioethics itself, and in the practical contexts in which the recommendations made by bioethicists are designed to have effect. Feminist empirical bioethics seeks to put forward “a toolkit for critical engagement with the politics of ethical and bioethical life”. As a methodology, Scully’s account of feminist empirical bioethics is one that allows a light to be shone on oppressive practices, advancing anti-oppressive and equality-based norms, by seeking to reveal imbalanced power structures, stressing the moral significance of human relationships and care, and placing marginalised voices at the heart of the process of identifying and analysing issues of ethical concern within society. As Scully attests, the justificatory foundations of feminist empirical bioethics are strongly anti-relativist, with empirical work functioning to advance ways of being and acting in the world that function to prevent exploitation, abuse, and oppression.

Whilst these four methodological approaches represent only a snapshot of the methodological field of empirical bioethics research in its current form, even a cursory glance at the chapters below reveals some immediate and important differences. Landeweer et al. and van Thiel & van Delden seek to make methodological progress by clarifying a justificatory account of how practical ethical knowledge can be obtained. Relating back to different meta-ethical commitments, such knowledge is contingent on a central role being given to dialogical interpretation in the former and, in the latter, to the argumentative force of moral intuitions and coherence. In contrast, Kim’s methodological approach is justified by recourse to a particular political arrangement and to the explicit recognition that standards of democratic political involvement ought to be endorsed when bioethical research activities are orientated towards the formulation of public policy recommendations. Scully’s feminist EB methodology is one that gains traction and justification through its prior commitment to a set of normative values that require socio-cultural biases against women and other marginalised groups to be challenged. Scully argues that her account of an empirically-grounded bioethics that seeks to foreground the voices of those who experience oppression, or who are otherwise side-lined in the hegemonic discourses of contemporary ethical analysis, is the only way to enact these moral norms in invoking practical ethical changes in the world.

In thinking about whether these approaches ought to be enacted in a piece of bioethics research, it is important to recognise that they are not exempt from criticism. Those who are digesting the different

approaches with a view to selecting a methodology for their own research would be well placed to reflect on a number of questions that concern both the justifications and design decisions that form part of these methodological strategies. We suggest that the following kinds of questions could usefully be posed by bioethicists who are seeking to select a methodology in their own research work:

- Is the justificatory account underpinning the need to, and way of, integrating empirical and ethical analysis to resolve a specific practical ethical issue clear? Does this justification hinge on a meta-ethical, political, or normative ethical commitment? How might such a justification be challenged, and how would you defend the implicit theoretical commitments that the methodology is built upon?
- Is the methodological design consistent with this justificatory account, and is it clear precisely how the analytic process ought to take place in a way that can provide sound normative conclusions?
- What specific disciplinary conventions accompany the methodologies or methods selected, and how might these conventions be managed or amended when the EB researcher is working in a transdisciplinary fashion?

### **Novel Research Practices**

The final two chapters in Section 2 move away from distinctive methodologies to offer a set of remarks about the wider challenge of forging a research identity and career in a field of inquiry that sits firmly outside standard disciplinary conventions. How can empirical bioethicists go about the business of conducting their research, even when they are armed with a methodological framework that they believe is best-placed to make justified normative conclusions; and how should these conclusions be disseminated and enacted? The points outlined in the final two chapters seek to engage with this question.

Showcasing such concerns is important, we believe, because of the transdisciplinary quality of empirical bioethics methodological practice. In contrast to similar methodological approaches that are commonly adopted in the social sciences, empirical bioethicists are striving to articulate the added value that their novel approaches bring, whilst simultaneously attempting to develop research identities within broad fields of inquiry that remain demarcated in more circumscribed and disciplinary terms. How should this balance be struck?

There are both attitudinal and practical considerations to attend to in answering this question. Empirical bioethics needs to give careful thought to how its practitioners ought to make sense of their research identity, and how they ought to conduct themselves, when they are engaged in a set of methodological activities that are both novel and emergent. In a recent paper that speaks to this issue, Mertz et al. (2014) argue that a 'road map for quality criteria' can be beneficial. Seeking to attend to this transdisciplinary concern by articulating a set of core standards for empirical bioethics research, their proposal borrows quality criteria articulated within philosophy and social science, but also identifies novel criteria necessary for attempts to integrate analytic approaches between disciplines. Their 'interdisciplinary highway' focuses on core study design and relevance criteria. The former set of issues require the empirical bioethics researcher to be clear on i) the research question, ii) the theoretical framework selected to justify and shape the integration of different empirical and ethical approaches, and iii) the corresponding methods adopted. The latter set of criteria require researchers to give careful consideration to the epistemic and social value of these design decisions (i.e. attending to implicit normativity in the research process).

The shift to identifying generalisable standards in EB research is a laudable aim, particularly given the value of coalescing around shared practices when methodological diversity is such a significant feature of empirical bioethics research.. However, at a closer glance, Mertz et al's proposal is focused more on provoking empirical bioethics researchers to reflect carefully on the choices they make in their studies, rather than in articulating clearly defensible standards of research conduct. Until further work on practice standards in empirical bioethics research has been completed,<sup>63</sup> we would strongly endorse this position.

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<sup>63</sup> Such as the ongoing work on a European consensus building project on standards in empirical bioethics research, hosted at the Brocher Foundation in May 2015, and chaired by Jonathan Ives, Michael Dunn, Bert Molewijk and Jan Schildman.

Thus, a central requirement of research conduct in empirical bioethics requires an explicit and continual reflexive stance to be adopted when engaged in one's research activities. In practice, this partially means giving due consideration to how one would defend the integrative dimensions of the research strategies adopted, or the methods deployed, as Mertz et al. claim. However, it also means recognising that conducting ethical reasoning in novel ways, and in new interpersonal spaces of inquiry, requires the EB researcher to consider how her own identity, uncertainties, and interactions with participants in the research setting, are negotiated and managed at each and every stage of the process. It means being aware that engaging in ethical reasoning in these ways can be potentially transformative and disruptive to the moral identities of study participants. Not every individual who comes into contact with an EB researcher is, after all, likely to be as familiar with the process of developing, justifying and critiquing ethical arguments as the researcher herself; and the potential for disruption is significant. Ensuring that these concerns are reflected upon, that the methodological process is amended as appropriate, and that each and every step of this process is documented and written into a research report, is also likely to be a necessary component of good EB research.

An orientation towards reflexivity in bioethics research has been defended elsewhere (Ives & Dunn, 2010), but such reflexivity looks to be of even more crucial significance in the context of empirical bioethics research settings, and this justification is not simply reflective of the need to attend to standards of research practice drawn from the social sciences, as Singh describes in her chapter in this volume. A more appropriate way of accounting for this reflexivity might be to understand it in terms of the concept of 'moral craftsmanship' articulated by Parker (2012). Whilst Parker deploys this notion to explain the ways in which clinical genetics professionals attend to the moral dimensions of their work, the focus of craftsmanship on how individuals strive to proactively seek out, manage, and continually re-evaluate both problems and solutions in moral matters lends itself to being applied in this context. In this sense, we might think that empirical bioethics researchers are engaged in the 'moral craft' of undertaking novel forms of bioethics research, managing emerging difficulties and uncertainties as they traverse stable disciplinary standards in their research endeavours, striving to craft ethical arguments that have practical force in new and creative ways.

This standard of reflexivity is taken up proactively in Chapter 11. Here, Farsides & Williams write as a medical ethicist and medical sociologist respectively. They offer extensive and detailed reflections on their own experiences of dealing with the methodological challenges of interdisciplinary research in a number of studies of morally contested areas of biomedicine. Working to develop their own methodological approach, and to adapt specific methods to conduct their research, the authors demonstrate that many of the challenges they faced extended beyond high-level methodological difficulties. Instead, Farsides & Williams discuss the challenge of gaining buy-in (from funding bodies, academic institutions, research ethics committees, and healthcare practice settings amongst others) when the activities involved are novel and difficult to situate within standard disciplinary paradigms. They also discuss the organisational difficulties that can emerge in empirical bioethics research that involves the facilitation of discussions between stakeholders of different types. Farsides & Williams remind us that it can be a logistical issue to organise times in which practitioners, managers, patients and family carers are able to sit down together to discuss ethical issues, and an intellectual and interpersonal challenge to facilitate groups of people that are characterised by pre-existing power dynamics and expectations (an issue that is also discussed by Landeweer et al. and Kim in this volume).

The final chapter in Section 2 focuses on practical research challenges in empirical bioethics that extend beyond the moment of the research activity itself. Frith & Draper explore how empirical bioethics research can be reported and published, given its novel and interdisciplinary qualities. They consider the possibility of splitting up the more empirical and ethical phases of research inquiry in empirical bioethics, suggesting that researchers might seek to publish the outcomes of these components of research in the journals aligned with their respective disciplinary approach. Of course, an obvious concern that Frith & Draper consider is the viability of such a separation; certainly in the methodologies showcased in this book, the integration of empirical and ethical components in empirical bioethics research is such that the substance and outcome of the activity may no longer be separable. They also consider the possibility of separating the outcomes of a piece of empirical bioethics research, and publishing these outcomes separately. There are both practical and ethical concerns with this approach, as Frith & Draper explicate, including the risk of the richness of the data being sacrificed for pragmatic reasons. Their conclusion is – at least for the time being – pessimistic;

any strategy for publishing empirical bioethics research in the dominant paradigms for disseminating bioethics research will necessarily involve making compromises.

## Conclusions

Developing research methodology in empirical bioethics has been, and is likely to remain, a strong focus of work in the field. However, without communication between those advocating different approaches, particularly concerning questions of justification and research design, there remains the very real risk that empirical bioethics will devolve into a fragmented grouping of different methodological silos that track pre-existing schisms in philosophy and the social sciences.

The chapters below show that developing research methodologies in empirical bioethics means attending to central epistemological and meta-ethical commitments, and progress is contingent on defending these commitments in response to those articulating different justifications and methodological frameworks. One way of ensuring that progress in the field remains possible is for those involved in formulating empirical bioethics methodologies to seek to identify common research standards that can be agreed upon, regardless of the main philosophical differences between those working in the field. Further work here will undoubtedly be fruitful in maintaining the pace and progress that methodological development in empirical bioethics research has enjoyed over the last decade, and our hope is that this volume will stimulate the kind of interest and debate that will facilitate that continued development.

## References

- Abma T. Baur V. Molewijk B. Widdershoven G. 2010. Inter-ethics: towards an interactive and interdependent bioethics. *Bioethics*, 24(5):242-255.
- Abma, T. Molewijk B. Widdershoven G. (2009). Good care in ongoing dialogues. Responsive evaluation and moral deliberation. *Health Care Analysis*; 17 (3): 217-35.
- Davies R, Ives J, Dunn M, (2015) A Systematic Review of Empirical Bioethics Methodologies. *BMC Medical Ethics*, 16.
- Dunn M, Sheehan M. Hope T. Parker M. (2012). Towards methodological innovation in empirical ethics in research. *Cambridge Quarterly of Healthcare Ethics*. 21 (4) 466-480
- Frith L. (2012). Symbiotic empirical ethics: a practical methodology. *Bioethics*, 26 (4), 198-206
- Gutmann, A. & Thompson, D. 2004. *Why Deliberative Democracy?* Princeton, NJ: Princeton University Press.
- Ives J. A method of reflexive balancing in a pragmatic, interdisciplinary and reflexive bioethics. *Bioethics* 2014;28(6):302-312
- Ives, J. and Dunn, M. 2010. 'Who's Arguing? A Call for Reflexivity in Bioethics', *Bioethics* 24(5): 256-265.
- Molewijk, B, Stiggelbout A, Otten W, Dupuis H, Kievit J. (2004). Empirical data and moral theory. A plea for integrated empirical ethics. *Medicine, Health Care and Philosophy*. 7 (1), 55-69
- Mertz M. Inthorn J. Renz G. Rothenberger L. Salloch S. Schildman J. Wohlke S. Schicktanz S. 2014. Research across the disciplines: a road map for quality criteria in empirical ethics research. *BMC Medical Ethics*, 15:17.
- Parker M. 2012. *Ethical Problems and Genetics Practice*. Cambridge: Cambridge University Press

Voskes, Y., Kemper, M., Landeweer, E.G.M. & Widdershoven, G.A.M. (2013). Preventing seclusion in psychiatry: A care ethics perspective on the first five minutes at admission. *Nursing Ethics*. Online First, DOI: 10.1177/0969733013493217

Widdershoven, G (2001). Dialogue in evaluation: A hermeneutic perspective. *Evaluation*, 7(2), 253–263.

Widdershoven G. Abma T. Molewijk B (2009a). Empirical ethics as a dialogical practice. *Bioethics*, 23 : 236-248.

Widdershoven, G, Molewijk B. Abma B (2009b). Improving care and ethics: a plea for interactive empirical ethics. *Am J Bioethics*. 9 (6-7), 99-101



# Moral improvement through interactive research: A practice example of dialogical empirical bioethics

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How to do empirical ethics research and what to learn from it? There are many theoretical conceptual discussions related to empirical ethics research, but less attention is paid to how empirical ethics research is done and how it contributes to health care practice. In this chapter we will describe an empirical ethical research project, which combines social scientific methods with normative aims and reflections.

The chapter presents a specific kind of empirical ethics: *dialogical* empirical ethics. It describes our methodology, aiming to include stakeholders in a process of reflection and dialogue on moral issues in practice, resulting in joint moral learning and improvement of practice. The methodology will be illustrated by an empirical study, which aimed to foster reflection on the moral appropriateness of coercive measures and on developing moral solutions regarding the reduction of coercive measures, by stimulating dialogue between nursing teams. First, we will describe the theoretical framework and the normative underpinnings of the research methodology. Second, the research setting and activities will be outlined. Next, the main results will be described. After that, we will reflect on the methodological process of co-creating moral knowledge and fostering moral improvement in practice.

We will end with some conclusions regarding the contribution of empirical ethical research to moral improvement in practice, and some challenges involved in making empirical ethical research into a well-qualified methodology for moral improvement of health care practice.

## Theoretical framework: Dialogical empirical ethics research

Interest in empirical ethics has increased during the last decade, giving rise to a wide variety of viewpoints on its theoretical (normative) underpinnings and its methodological characteristics (Molewijk et al, 2009; Solbakk, 2012).<sup>64</sup> Relatively few papers explicitly focus on the concrete methodology of empirical ethics (Molewijk et al, 2004 & 2012; Widdershoven et al, 2009a/b; Frith, 2012; Dunn et al, 2012). Salloch and colleagues point towards the fact that many empirical ethics studies lack normative analysis and are merely crypto-normative, as "... they implicitly take normative statements as the basis of their ethical argumentation without mentioning or reflecting on them" (Salloch et al, 2012:3). In order to avoid this, we will describe in this section the theoretical and normative underpinnings of what we conceive as 'dialogical empirical ethics', how we deal with normativity, and how we perceive the role of the researcher in this approach to empirical ethics.

### *Theoretical and normative underpinnings of dialogical empirical ethics research*

Our notion of dialogical empirical ethics research is based upon hermeneutic philosophy (Gadamer, 1960) and responsive evaluation as an empirical research method (Guba & Lincoln, 1989). In line with hermeneutic philosophy, our approach is based on experiences in practice and aims to bring together various normative perspectives in dialogue. In line with responsive evaluation, it implies working closely together with participants in the practice, who are regarded as 'stakeholders' or partners in the whole research process (i.e. designing the empirical research process, developing the research questions, interpreting the results, and drawing normative conclusions). This is different from other types of empirical ethics research, in which the researcher reflects on empirical data (sometimes collected by other researchers), and draws normative conclusions by him/herself alone or with peers.

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<sup>64</sup> See for example the thematic issues on empirical ethics of *Bioethics* in 2009 and of *Cambridge Quarterly* in 2012.

The term 'dialogical' refers to a dialogue between practice and theory, between the ethical and the empirical research, and between ethics and practice. However, above all, dialogue in our empirical ethics research refers to interaction between various people with various roles, both practitioners and researchers, jointly exploring what is morally right.

According to Gadamer, hermeneutics start from the basic viewpoint that human life is a process of interpretation. Hence, hermeneutic ethics focuses on how human beings interpret the situation morally. This interpretation is an on-going process and depends strongly on context and experiences. Hermeneutic ethics consists of three key elements: the notion of perspective, dialogue as a learning process, and practical rationality. The notion of perspective refers to the fact that human beings interpret the situation from a certain point of view based on former experiences. A perspective can be implicit or explicit, and is always partial. This is not problematic: it is the initial departure point of any reflection and normative judgment.

Complementary to the notion of perspective is that of dialogue. Differences in perspective call for dialogue and exchange. Dialogue requires openness towards the other, and being prepared to investigate the validity of the other's point of view:

Dialogical understanding means that one tries to see the point the other person makes. It means being open to what the other has to say (instead of ignoring the response) and being prepared to accept it as potentially relevant and valid for oneself (Widdershoven et al, 2009a:238).

Dialogue is not merely an instrument in order to reach morally better decisions or a higher compliance in moral decision making processes. Furthermore, it not only refers to reasoning as a rational and cognitive process, but also involves taking into account emotions and meeting the other as a person. Dialogue involves moral learning, as situations are reconsidered and revalued based on new interpretations and understandings in which initial presumptions are challenged and fuelled with other perspectives.

Within a dialogue, participants come from different places and have different historical and cultural backgrounds, resulting in prejudices, which embody various values and meanings. Every participant in a dialogue has his/her own dynamic horizon:

The horizon is the range of vision that includes everything that can be seen from a particular point of view (...) The word has been used in philosophy to characterise the way in which thought is bound to a perspective, and the way in which one's range of vision is gradually expanded. (Gadamer, 1960:286)

A horizon is not fixed, but flexible; one can go beyond one's current point of view by taking another stance and looking from a different angle. In a dialogue, the participants interpret each other's views from their own perspective, but also aim to understand the perspective of the other, and see its relevance. According to Gadamer, a successful dialogue results in a fusion of horizons:

To reach an understanding in a dialogue is not merely a matter of putting oneself forward and asserting one's point of view, but being transformed into a communion in which we do not remain what we were. (Gadamer, 1960:360).

The third key element, practical rationality, refers to the fact that the stakeholders in general are considered to have practical knowledge of what is morally important and right. This knowledge is contextual and situated. The stakeholders know from experience what is morally relevant and are able to discern what matters in a specific situation. This does not imply that the stakeholders have a final view on what is morally justified: practical rationality is further improved by experience and dialogue. Morality in practice is seen as an on-going negotiation, a process in which practical rationality is expressed, reviewed and further developed.

Responsive evaluation approaches to empirical ethics research aim to enhance the personal and mutual understanding of a situation by fostering on-going dialogues and joint reflection on relevant issues among various stakeholders (Abma et al, 2009a). With respect to empirical ethics, this means

that various stakeholders (including the empirical ethics researchers) reflect on implicit and explicit moral issues that play a role in the practice under study. A whole set of techniques is available to identify these moral issues, including in-depth interviews, brainstorming sessions, discussion meetings, moral case deliberations, and focus groups. A dialogical approach implies that the stakeholders present their issues and concerns, but also respond to the issues of others in order to obtain a shared understanding. A shared understanding does not automatically imply that there is (or should be) a consensus or mutual agreement. Differences can lead to a learning process (Widdershoven, 2001). The empirical ethics researcher charts the research progress and keeps track of his or her role in the research process. A dialogical attitude refers to an active and critical exploration of each other's moral thinking and judgments. The responsive evaluation researcher tries to foster and support openness, respect, inclusion and engagement (Greene, 2001).

To summarise, the theoretical and normative underpinnings of dialogical empirical ethics entail that moral knowledge is based on practical experience and perspective, calls for and is fostered by dialogue, and requires openness and awareness that moral insights are temporal and part of an on-going process, which can be stimulated and improved by empirical ethics research. Facilitating dialogue between different perspectives is, therefore, an important normative condition and assignment for scientists who conduct dialogical empirical ethical research.

#### *Normativity within dialogical empirical ethics research*

Dialogical empirical ethics focuses, as the term 'ethics' indicates, on moral issues, moral reasoning and moral judgments. The primary focus is on the moral issues, moral reasoning and moral judgments of the stakeholders. Yet, dialogical empirical ethics is not merely 'descriptive research'. It starts from normative choices about research questions and settings, and normative decisions about who counts as relevant stakeholders related to the research question. It further includes a normative analysis of, and conclusion on, moral issues of stakeholders (Molewijk & Widdershoven, 2012). In dialogical empirical ethics, the choice of the research question and the stakeholders, the normative analysis of the data and the normative conclusion, are derived *in* and *with* the practice under study. Within the process of analysis and drawing normative conclusions, other 'external' considerations can also play a role. For example, the researcher might bring in a certain viewpoint or concept that has not been considered thus far, or refer to a certain moral theory that might shed light on the moral issue at stake. Yet the relevance of such considerations should be acknowledged by participants, and they should be related to the practical experiences of those who take part in the dialogue (Landeweer et al, 2011).

For the joint process of drawing conclusions in dialogical empirical ethics research, two criteria are important. In the first place, normative conclusions should be developed in a process of joint investigation. By exchanging perspectives, participants in dialogue develop new and shared views on what is morally right. In the second place, no stakeholder contribution involved in the process of drawing normative conclusions has a higher epistemological or moral status than any other. In the end, drawing normative conclusions is not about finding proof that shows that the products of the dialogue are right (that is, looking for a justification), but about moving towards better accounts and increasing our mutual understanding on what is morally appropriate in the specified circumstances (Frith, 2012; Hughes, 2001; Beauchamp, 2000). The process of drawing normative conclusions is not limited to discussing arguments and principles, but also consists of sharing and reflecting on practical experiences. Thus, normative conclusions are not abstract, but directly based on concrete and situated insights, which are open for joint investigation.

#### *The role of the researcher within dialogical empirical ethics research*

Within dialogical empirical ethics research, the researcher not only interprets the issues of stakeholders within a certain practice, but also acts as a facilitator of the interpretation and negotiation process between the stakeholders. The formulation of the research aims and setting, and the normative evaluation process are not directed by the researcher only but are organized in interaction

with participants in practice (Widdershoven et al, 2009a). The researcher has various roles, such as interpreter, educator, facilitator and Socratic guide. The role of interpreter indicates that the researcher has to focus on the meaning of issues and be sensitive to various perspectives on situations, findings and conclusions. The role of educator implies that the researcher should actively support the learning process and the creation of understanding by explicating various experiences to involved groups. The role of facilitator refers to the organisation of a dialogue among stakeholders and the creation of required conditions. In the role of Socratic guide, the evaluator will probe into taken for granted ideas, final truths and certainties, and bring in new meanings and perspectives (Schwandt, 2001; Abma et al, 2009a).

Within dialogical empirical ethics research, the normativity of the researcher is acknowledged and explicitly taken into account. First, the researcher will have his- or her own normative motive. These are related to the conviction that dialogue is important for moral learning. Thus, the researcher acts from the presupposition that it is important to create room for experiences and to include all relevant stakeholders in the process of improving moral practice. Ideals of equality and democracy influence the way in which the researcher views the practice under consideration and responds to what happens. Thus, the researcher will be sensitive to and critical of differences of power or processes of exclusion, both with respect to persons and specific viewpoints. In principle, the researcher will be focused on the conditions and moral expectations in a given practice in order to foster openness and mutual learning. Second, the researcher might have normative considerations, ideas or opinions regarding the subject under study. The researcher will not start to present these immediately, but will explore them in response of what the stakeholders present and express. When doing so, the researcher does not present his or her views as superior, but questions existing rules and relationships and critically examines existing presuppositions. The researcher does not judge the practice under consideration as a final arbiter, but does give normative input by raising questions and inviting participants to reflect and deliberate in more equal and open ways.

### **A example of dialogical empirical ethics: Improving the practice around seclusion by organising an exchange program for nurses at different psychiatric wards**

#### *Background*

In 2006, a mental health institution in the Netherlands started a project aimed at reducing the amount of coercion and restraint of psychiatric patients. The central focus of the program was to improve contact and communication with the patient in the first phase of interactions. This initiative was called 'The first five minutes', indicating the importance of adequate attention for the patient from the very beginning of each interaction (Voskes et al, 2013). The slogan that was used for this project was: 'You never get a second chance to make a first impression.'

As part of the project, professionals working at the three closed wards participating in this study were invited to develop and implement creative interventions to improve contact with patients on their wards. These so called 'best practices' focused on improving staff attitudes, working routines, and treatment procedures. The wards were invited to create new practices and strategies to prevent the use of coercion, with financial support of the management.

The project was based on the assumption that wards would take over successful practices and strategies from each other. This, however, did not happen automatically. Moreover, the three closed wards of the mental health institution were not equally enthusiastic about the project. In order to facilitate the spread of successful interventions and foster enthusiasm about reducing coercion, researchers and management developed and organised an exchange program with psychiatric nurses between the three closed wards. The idea was to stimulate and inspire the nurses to morally reflect and learn from each other's strategies.

The exchange program aimed to foster insight into differences between wards and to stimulate a dialogue between nurses on how to understand, and subsequently morally improve, their practice,

and learn from each other. It aimed to enable the nurses to experience how other teams worked, to hear and experience what other nurses considered to be best practice regarding the prevention of the use of coercion, and to reflect on how these best practices might work within their own ward. The project was monitored and supported by researchers, who described how the exchange was experienced and which changes were realised. A core element in this project was that researchers organised and stimulated dialogue and reflection on best practice between the nurses, in order to foster (moral) learning concerning how to deal with complex moral issues involved in the prevention and use of seclusion.

### *Organisation*

The exchange program took place in a period of two months. In the first month, two nurses of each ward changed working places and worked at another ward. In the second month, two other nurses assisted at another ward. In total 12 nurses participated in the exchange program. After two days of adjustment (i.e. learning time) the guest nurses who took part in the exchange program participated fully in the host team. They were selected based on willingness, and varied in working experience to stimulate diversity. They were asked to be open and look for differences in working routines and possible learning points for their own wards.

### *Research method*

To monitor and facilitate the exchange program, a qualitative responsive research method was used (Abma et al, 2009a). This method aimed to foster quality improvements through reflections and dialogues between the participants of the program. Data collection existed in weekly logbooks (to be filled in by the 12 nurses), interviews and focus groups. The nurses who participated in the exchange program were asked to report weekly on their experiences and observations by writing in a logbook. Also interviews were conducted with the nurses before and during the exchange period. After each month a focus group meeting was organised with the nurses (n=6) to evaluate their experiences and discuss mutual insights. In the interviews we focused not only on differences between the wards, we also asked the nurses which practices and aspects they considered good and new to them.

All interviews and focus groups were audio taped and entirely transcribed. Then four rounds of validity checks with all stakeholders followed. First, central interpretations were peer- debriefed and member checked among the researchers to foster credibility. Thereafter, these interpretations were validated with the respondents using summaries. Central topics that were found in the interviews were then discussed in focus groups. Next, the results were discussed with the project group members and team managers of the three participating wards. Finally, preliminary conclusions were presented at the wards to check for authentic representation of experiences. After a year, the team managers were consulted to get insight into long-term results of the exchange program.

### *Results*

All participants considered the exchange program as profitable and inspiring, as it created new insights into why and how certain decisions were made and gave openings to improvements of practice. The nurses saw many differences between the wards and found their stay at the other wards useful:

It created a new perspective regarding my own ward. When I got back I noticed more things that we do well and things we still can improve. (nurse)

The differences experienced by the nurses concerned *cultural aspects* of the wards (i.e. dominant values and norms), procedures and *working routines*, and the *structure* (organisation) of the wards (Abma et al, 2009b). Although all wards a priori agreed on the importance of reducing coercion, normative views (for example concerning the importance of safety or being attentive towards patients)

differed. Procedures and routines were also different, for instance regarding the moment of intervention in case of tensions between patients and staff, the content of safety protocols and their use, or how quickly one should react to a patient's request. At the level of structure, the wards showed differences in physical environment, facilities and level of comfort for patients.

Differences in culture and structure influenced working procedures and routines at the wards and vice versa. This resulted in some interventions being more easily developed, implemented and secured on one ward than on another. For example, one of the wards in a more peripheral location had a team of nurses, closely working together with each other, the team manager and a psychiatrist. The psychiatrist trusted the nurses in making decisions. The responsibility for decisions regarding how and when to use coercion were shared between nurses and the psychiatrist. Yet, the close culture made them spend more time in the office than on the ward, compared to the other teams. Thus, it was difficult in this ward to implement interventions aimed at fostering interaction between staff and patients.

In the focus group meeting, the differences between wards were discussed and analysed, resulting in moral learning. We will illustrate the process of moral learning and co-construction of new practices by elaborating on two examples. The examples are; (i) how to decide on the moment at which a patient is allowed to leave the seclusion room, and (ii) how to improve interaction between nurses and patients, by removing the separate office for nurses. Both examples show how the encounters in the exchange program, supported by analyses of the researchers, stimulated nurses to reconsider existing routines. The topics were jointly chosen by the researcher and project-management (i.e. the director and the project leader of the institution) to discuss in the focus groups. They related to the aims of the project to mutually analyse and stimulate processes of sharing best practice interventions between the wards.

#### *Deciding on allowing the patient to leave the seclusion room*

An important moral issue around seclusion concerns the decision to allow the patient to leave the seclusion room and return to the ward. This decision is precarious. Practitioners need to be sure there are no more risks involved for other persons. Yet, to determine safety is difficult and comes with uncertainties. During the exchange program, nurses became aware of differences between wards regarding decisions about allowing the patient to leave the seclusion room. In the focus group, the advantages and disadvantages of the different procedures were discussed.

On the first ward, the staff evaluated every hour whether the patient could leave the seclusion room as part of a protocol. They tended to take more risks, which sometimes implied the patient had to be secluded again:

We tend to take more risk in deciding to let the patient in the group again. At the other ward it seems to differ between the person [the psychiatrist on duty] who is authorised to make these decisions and that is an issue. They had some bad experiences, that is why they are more careful than we are. (nurse)

On the second ward, taking medication was regarded as a precondition for allowing the patient to return to the group. The argument was that if things get seriously out of hand, it is justified to start involuntary medication and treatment:

We consider it important to start with medication in the seclusion room (...) Otherwise the patient will end up back in the seclusion room again. That is how our psychiatrist thinks about it. (nurse)

On the third ward, protocols were not strictly followed. Working experience and intuition were regarded as crucial elements in deciding about allowing the patient to leave the seclusion room. The nurses became aware of the risk of patients remaining longer in the seclusion room after several bad experiences:

It has two sides. To follow your gut feeling is important, but it can also go wrong. Yet, if you don't have a good feeling about it, you are to listen to that too. Protocols do help you back up your gut feelings. (nurse).

The differences in approach between the wards made the nurses realise that routines and bad experiences may influence decisions and create arbitrariness; the time a patient stays in seclusion may depend on the ward to which he is admitted. While professionals on all three wards intended to use the seclusion room only when it was absolutely necessary, their decisions about when to stop seclusion were based on different choices. The overall conclusion in the focus group was that each ward should develop explicit policies and procedures regarding the decision to allow a patient to leave the seclusion room. Applying these policies and procedures entails individual judgment, but gut feelings should not be the sole base for decisions; certainly not if the consequence would be that patients stay longer in the seclusion room. It was also concluded that protocols should be evaluated regularly together, to help prevent the negative influence of routines and bad experiences. Thus, becoming aware of other ways of working regarding the decision to end seclusion, broadened the nurses' perspective and enabled them to develop new and shared ways of improving decision procedures.

#### *Working without a nurses' office*

One of the wards had closed the office for nurses just before the exchange program, and established a counter desk at the ward. Although the nurses from the other two wards at first were sceptical about the idea not to have an office as a separate place to do administration and converse with colleagues, during the exchange they found that their worries were unwarranted. They experienced positive effects of working without a separate office:

Working without an office was new for me, but soon I experienced it as positive. You can see much more and are able to anticipate much faster. You are able to prevent escalations much better (nurse)

The counter desk had an impact on the daily work. It enabled the nurses to spend more time with the patients, but also made it necessary to explain to patients they cannot always be assisted immediately, since reports have to be written also:

" got used to working without an office quite soon, although I learned you have to be clear to patients when you need time to write your reports. A positive aspect is that you notice things sooner. (nurse)

After the exchange, the nurses of the other two wards were enthusiastic about working with a counter desk. They advocated this intervention at their own wards. Both wards decided to follow in the footsteps of the ward that had closed the separate office. In a follow-up contact one of the team managers emphasised that the exchange program had helped to convince the staff of the advantages of closing the office:

I see the exchange program as a powerful tool to create change. I had intended to close the office a while ago, but the nurses were against it. After the exchange program the participating nurses were very positive, and were able to convince the others of the advantages of closing the office. (team manager)

In this example, new insights were developed through experience. By experiencing other working routines, the nurses overcame prejudices regarding the use of a counter desk and were stimulated to consider advantages for their own wards.

The normative aim of the exchange project was to create learning processes through experience and dialogue. Regarding the issue of deciding when a patient would be allowed to leave the seclusion room, greater awareness of differences in approaches was created, which served as a start, and vehicle, for reconsidering routines and developing new protocols. Working with an open counter

instead of a separate office appeared inspiring, and resulted in changing the structure at the other wards.

## Discussion

Dialogical empirical ethics research aims to broaden horizons, and support participants to develop a new perspective on which values are important and how to embed them in practice. Through making explicit experiences and fostering exchanges of perspectives in dialogue, participants are invited to see moral aspects of their work from a broader point of view, and to develop new and better ways of dealing with moral problems in practice. This process of moral development through fusion of horizons can be recognised in the exchange project discussed above. By experiencing different approaches to decision making about removing patients from seclusion, the nurses became aware of the need to combine practical knowledge and protocols, and to evaluate the decisions that are being made. This new view implied a change in all three the wards, and a development of a more generally shared approach to decisions about ending seclusion. By actually working in a ward without a nurses' office, the nurses came to see the advantages of avoiding a structure that accentuates hierarchies, but does accentuate contact with the patients. In this case, the point of view of one of the wards was seen as valid, and consequently accepted and adopted, by the other two wards. Yet, this insight was not based on arguments in favour of closing down the nurses' office, as these arguments were already known, and had not convinced the staff at the other two wards when propagated by the management. This example shows that a process of fusion of horizons is not primarily a matter of argumentation, but a practical learning process in which reflection on concrete working experiences is crucial.

Conducting dialogical empirical ethics research is a rewarding activity as it increases both the insight of the researchers in moral issues and normative considerations in practice, and results in motivating research participants in practice to exchange views and come to new joint conclusions about what is morally right. Moreover, these two elements of dialogical empirical ethics are not distinct from one another. The researchers can only get insight into moral issues in practice by inviting participants to talk about their experiences and actually exchange experiences with each other. The insights, on the other hand, are fed back into practice through reports and proposals for the issues to be addressed in further dialogue meetings. While organising a process of making explicit experiences in practice and sharing them in dialogue, the researchers already change practice. They create conditions for openness and reflection, which result in new views and proposals for action. The researchers are actively involved in the learning process, as they arrange the invitation of stakeholders, make the agenda for the dialogue (based on their analysis of issues raised by practitioners in informal meetings and formal interviews), make suggestions for the interpretation of the results of deliberations, and assist in drawing conclusions for practice. The input of the researchers has a normative background, as it aims to create democratic conditions necessary for dialogue. It is also normative in that it entails a commitment with the issues at stake in morally improving practice. The researchers do not a priori formulate these issues, but they do take a stance towards what is morally important in practice. In the project described above, the researchers shared with the management the normative view that seclusion of patients should be prevented, and that further improvement in this area was needed, as the wards did not automatically implement positive interventions developed elsewhere.

Dialogical empirical ethics implies a systematic investigation of experiences in practice and a structured procedure of organising reflection and dialogue between participants. As a scientific research method it shows similarities with action research (Reason & Bradbury, 2001), in that it aims to develop and improve practice in a cyclical iterative process. Like action research, it fosters insight into routines, culture and structure of a practice, and supports participants in practice to develop new ways of dealing with problems, by collecting data and organising feedback to participants in practice in a systematic way. In contrast to standard action research, dialogical empirical ethics explicitly focuses on moral aspects of a practice. Furthermore, dialogical empirical ethics research always tries to improve practice through dialogical research processes in which the actual improvement is determined during the research process. This is done collaboratively with all the stakeholders; aiming



to develop rich moral descriptions and to foster moral reflection and joint moral learning, in order to create changes in practice, which are moral improvements.

Dialogical empirical ethics research implies several challenges. The first is how to ensure that the right research questions are formulated and the right groups are involved in the research process. Given that research questions are based on normative assumptions, both the researchers and other parties in practice who are involved in the development of the research plan should reflect on the choice of the questions central to the research project, and be transparent about the assumptions. A presupposition of the nurse exchange project was that seclusion is morally problematic and should be reduced. A further presupposition was that processes of change, leading to improvement of practice, require insight into cultural and organisational differences between the wards. Based on these normative assumptions, the research question was to investigate whether and how an exchange of nurses between the wards could foster a dialogue on moral improvements without respondents feeling threatened or forced to change their practices. Nurses were invited to take part in the exchange programme, which was supported by the management. Thus, the nurses and the management of the wards were regarded as the main stakeholders in the project. In order to ensure that these two stakeholder groups had a shared vision of the research objective, the research question and its normative presuppositions were openly discussed with the nurses who opted for participation in the exchange programme. Other staff at the three wards was also informed and asked for consent. So, the normative aspects of the research aim, design and questions were shared between management, staff and researchers and agreed upon. Other potential stakeholders, such as patients and family, were not involved in this process, as they were considered to be only indirectly involved. This approach might be questioned, and one might for instance argue that patients should be involved, both in the formulation of the research question and in the further research activities. Our view is that such decisions cannot be solved beforehand, but should be transparent and open for discussion and revision.

Another challenge is how to be normative and how to draw normative conclusions. As mentioned above, we consider the researchers in dialogical empirical research as normative agents who take part in the learning process. The normativity of the research is reflected in the normative aim of the research: moral improvements in the practice of coercion. Based on that aim, the research design and instruments are chosen. Two other normative elements are important: being transparent about the normative aim and assumptions of the research(ers) (i.e. no hidden agenda or manipulation of the stakeholders) and fostering a mutual process of moral learning for both researchers and research participants (i.e. not a one-way learning process). Finally, openness regarding the normative results or conclusions of the research process is also a basic normative element of dialogical empirical research. Even though the research starts with a normative aim and research question, researchers and research participants are asked to have an open mind regarding the final normative answers.

A third challenge in dialogical empirical ethics research is how to validate the results. One of the aims of dialogical empirical ethics is to increase mutual understanding on what is morally appropriate in certain circumstances. The question then is how to ascertain that mutual understanding is improved, and how to be sure that this also results in a morally better practice. In the exchange program, a growth of awareness about routines could be established, as well as the intention to change practice, by developing new ways of dealing with protocols and by closing down separate nurses' offices. Yet, the question remains whether these changes actually reflect moral improvements. Opponents of dialogical empirical ethics might argue that fostering mutual understanding might in fact strengthen and justify certain practices that are morally wrong. This might, for instance, result in justification of procedures that imply that patients stay longer in the seclusion room. Such criticism presupposes an external normative framework through which we can determine whether a certain conclusion is morally right or wrong. Within dialogical empirical ethics research, the existence of an external framework or final arbiter is not assumed. Yet, the researcher will be aware of possible criticisms and incorporate these into the moral inquiry with the stakeholders. Furthermore, the question 'How do you know that this conclusion is morally right', is addressed within the research itself, again together with the stakeholders. Dialogical empirical ethics aims to foster critical investigation of possible conclusions by organising interaction between various perspectives (Landeweer et al, 2011). In the research project presented above, we arranged critical reflection processes from various perspectives

by involving various stakeholders. Nevertheless, it is a challenge to create circumstances in which participants feel safe to critically reflect on their own ideas for improvements and bring them into the dialogue. Researchers have to be sensitive to the culture and routines of the practice, and find methods to create openness for constructive disagreement and critical change. The researchers' role is not to establish which values and norms should guide practice, but they will inevitably have a view on both existing rules and new ones proposed by participants during the research process. In case they continue to have doubts, even after inviting other stakeholders and perspectives, the researchers' interventions consist in addressing problematic issues and raising critical questions. This criticism is positioned *within* the same framework and practice of the research, which is an on-going dialogue with the stakeholders (i.e. we do not position the criticism after or outside the framework of the research). In the context of dialogical empirical ethics research, these actions can be regarded not as final normative judgements about practice, but as contributions to the process of searching for new and better ways of dealing with normative issues in practice. In the end, the aim of dialogical empirical research is not drawing a final normative judgement *about the practice* in the research report or the research papers, but creating a process of mutual moral learning *in and with practice* in order to improve the quality of care in a concrete health care setting.

A final challenge for dialogical ethics research projects is to sustain the results that are obtained. Stimulating and facilitating dialogue between stakeholders not only aims to develop new insights, but also to create a breeding ground in practice for continuation of openness and reflection regarding moral subjects. For this, further commitment of practitioners and management is necessary. Implementing results of dialogical empirical ethics research requires both bottom-up engagement of professionals in practice, and top down support of middle and top management. Next to fostering insights, arguments and moral judgments, the researchers and stakeholders focus on how to implement these through new or adjusted work processes and structures. This process of implementation may be facilitated by organising follow-up research in order to monitor whether, and how, the lessons learned are implemented.

## Conclusions

In this chapter we presented a specific approach to empirical ethics: *dialogical* empirical ethics research. The aim of this type of empirical ethics is to include participants in practice in a process of reflection and dialogue on moral issues, resulting in joint moral learning and improvement of practice. We have elaborated on the theoretical background and the normative assumptions of dialogical empirical ethics, and described how it works in practice. We presented an example of a research project involving the exchange of nurses between three psychiatric wards, which aimed at creating learning processes regarding coercion, and fostering new ways of working which can help to reduce coercion. We also discussed some of the challenges involved in the practice of dialogical empirical ethics.

Dialogical empirical ethics research aims to create a systematic process of exchange of, and between, stakeholder perspectives; making participants aware of the presuppositions in their approach and fostering openness to other ways of working. The role of the researchers is to create conditions for reflection and exchange, and to stimulate such processes by asking questions, providing suggestions for interpreting differences, and inviting participants to draw normative conclusions that may lead to new actions and experiments. By making explicit moral considerations in practice, and inviting practitioners to reflect and exchange views, dialogical empirical ethics research may contribute to moral development in practice; not by providing moral arguments and drawing theoretically sound conclusions, but by supporting participants in clarifying moral experiences, and achieving joint insight into what matters in the situation. By gathering experience based data and organising systematic steps of reflection and dialogue, dialogical empirical ethics research can contribute to moral improvements in practice, and foster change at the level of routine, culture and structure.

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## References

- Abma, TA, Molewijk B. Widdershoven GAM (2009). Good care in ongoing dialogues. Responsive evaluation and moral deliberation. *Health Care Analysis*; 17 (3): 217-35.
- Abma, T. Voskes Y. Landeweer E. Emmaneel R. Scholten M. Kuijpers E. Richartz B. Bijmens L. Herrmann G. Widdershoven G.(2009). Lerende netwerken. Uitdagingen en oplossingen voor dwangreductie in de praktijk [Learning networks. Challenges and solutions for the reduction of coercion in practice]. *Maandblad Geestelijke volksgezondheid* (64) 6, p. 571-582
- Beauchamp, T. (2010). Reply to strong principlism and casuistry. *Journal of Medical Philosophy*, 25 (3), p. 342-347.
- Dunn M, Sheehan M. Hope T. Parker M. (2012). Towards methodological innovation in empirical ethics in research. *Cambridge Quarterly of Healthcare Ethics*. 21 (4) 466-480
- Frith L. (2012). Symbiotic empirical ethics: a practical methodology. *Bioethics*, 26 (4), 198-206
- Gadamer HG. (1960). *Wahrheit und Methode*. Tübingen: Mohr.
- Greene J. (2001). Dialogue in evaluation; A relational perspective. *Evaluation*, 7(2), 181–203.
- Guba E.G. Lincoln Y.S. (1989). *Fourth Generation Evaluation*. Beverly Hills CA: Sage.
- Hughes (2001). *Aristotle on ethics*. London, Routledge:115.
- Landeweer, E.G.M., Abma, T. Widdershoven G (2011). Moral margins concerning the use of coercion in psychiatry. *Nursing Ethics*, 18 (3), 304-316.
- Molewijk, B, Stiggelbout A, Otten W, Dupuis H, Kievit J. (2004). Empirical data and moral theory. A plea for integrated empirical ethics. *Medicine Health Care Philosophy*. 7 (1), 55-69
- Molewijk, B, Frith L. (2009). Empirical ethics: who is the Don Quixote? *Bioethics*. 23(4), ii-iv
- Molewijk, B, Widdershoven G. (2012). Don't solve the issues! A plea for ambiguity within empirical ethics. *Cambridge Quarterly of Healthcare Ethics*. 21 (4), 448-456
- Reason, P. Bradbury H (2001) *Handbook of action research: Participative inquiry and Practice*. Sage| London
- Salloch, Sabine, Jan Schildmann, Jochen Vollmann (2012). Empirical research in medical ethics: how conceptual accounts on normative-empirical collaboration may improve research practice. *BMC Medical Ethics*. 13 (5)
- Schwandt, T. A. (2001). A postscript on thinking about dialogue. *Evaluation*, 7(2), 264–276.
- Solbakk (2012). Guest editorial. Embedded ethics or fictitious facts? *Cambridge Quarterly of Healthcare Ethics*. 21(4) 419-425

Voskes, Y., Kemper, M., Landeweer, E.G.M. & Widdershoven, G.A.M. (2013). Preventing seclusion in psychiatry: A care ethics perspective on the first five minutes at admission. *Nursing Ethics*. Online First, DOI: 10.1177/0969733013493217

Widdershoven, G (2001). Dialogue in evaluation: A hermeneutic perspective. *Evaluation*, 7(2), 253–263.

Widdershoven G. Abma T. Molewijk B (2009a). Empirical ethics as a dialogical practice. *Bioethics*, 23 : 236-248.

Widdershoven, G, Molewijk B. Abma B (2009b). Improving care and ethics: a plea for interactive empirical ethics. *Am J Bioethics*. 9 (6-7), 99-101

# Reflective equilibrium as a normative empirical model: The case of Ashley X

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Ashley is a girl with profound developmental disabilities. At the age of six, she could not sit up, ambulate or use language. Ashley responds to others by vocalising and smiling. Improvement in her cognitive or neurological abilities is unexpected. In 2006, Ashley's physicians reported that they had medically treated her to arrest her growth and physical development (Gunther & Diekema, 2006). The treatment included hormone therapy for growth attenuation as well as surgical removal of early breast buds and Ashley's uterus. Ashley is now forever child-sized and according to her parents, her life is as good as it can be: she is their 'pillow angel' (Pillow Angel, 2014). Ashley's story went viral on the internet. The reactions varied enormously: some expressed the wish to make the treatment available to others (Allen et al, 2009), some found it ethically dubious (Isaacs et al, 2011), and another view was that Ashley was 'butchered' to meet her parents' needs (MSNBC, 2007). Since The Guardian reported in March 2012 that at least 12 other children were undergoing the 'Ashley Treatment', and disability rights advocates believe that thousands of families are considering it, the justification of growth attenuation treatment for this group of children has gained renewed attention (The Guardian, 2014).

Cases like Ashley's require ethical analysis and well-founded decisions on the acceptability of the treatment. There are, however, several methodologies that can be employed to arrive at such a decision. The question of which methodology is the most appropriate is at the heart of a long-standing debate (Anon, 2007; Ives & Draper, 2009). In this chapter, we outline a method for moral reasoning that starts from John Rawls's Reflective Equilibrium. We called it *Normative Empirical Reflective Equilibrium* (NE-RE). After the outline, we elaborate on some important criticisms of Reflective Equilibrium and their meaning for NE-RE. Subsequently, we analyse Ashley's case, aiming to demonstrate how NE-RE can be used to arrive at a justified view on the ethical acceptability of real life ethical dilemmas.

## **Normative empirical reflective equilibrium (ne-re)<sup>65</sup>**

Reflective Equilibrium was developed by John Rawls for the theoretical purpose of formulating the most appropriate conception of justice (Rawls, 1971). This ideal method of justification has later been distinguished from non-ideal models that aim at developing modest theories (Willigenburg, 1991) or can guide decision making in practical contexts (Arras, 2007). The term RE refers to a point in moral reasoning at which a (preferably broad) set of beliefs relevant to a moral case, form a coherent whole. In addition, RE is the description of a process of moral reasoning, aimed at justification of a moral view. Initially, two types of beliefs were taken up in RE: considered moral judgements and moral principles. Several authors have suggested amendments to the model, replacing some elements or introducing new ones (Daniels, 1979; Willigenburg, 1991). Currently, the beliefs that are potentially relevant to RE can be categorized in four groups:

- (i) considered moral judgements or moral intuitions;
- (ii) morally relevant facts;
- (iii) moral principles;
- (iv) background theories or ideals.

The best combination of elements depends on the purpose for which RE is employed.

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<sup>65</sup> See also Theil & Delden (2010)

NE-RE is an amended version of Reflective Equilibrium (RE). It comprises moral intuitions, moral principles, morally relevant facts and background theories. In addition, it has two distinct features:

- 1) Moral intuitions of relevant agents other than the Thinker are taken up.

Jmhv In most methods based on RE, the considered moral judgements or moral intuitions incorporated are the ones that come to the mind of the person performing the reasoning (we call him or her the Thinker). In some cases the Thinker is advised to broaden his scope by actively seeking 'formative experiences' (DePaul, 1993) or to explore anything that may be relevant through a process of open inquiry (Ives, 2014). Our proposal in NE-RE is to broaden the set of relevant beliefs by investigating the moral intuitions of persons other than the Thinker (Delden & Theil, 1998).

- 2) Empirical research is used to obtain data on moral intuitions or morally relevant facts.

This research can be valuable in obtaining unexpected insights and descriptions of the experience and interpretation from different perspectives or angles.

RE has both been welcomed and fiercely criticized. Two criticisms seem very important, and also pertinent to NE-RE: the role of intuitions and the nature of coherence.

#### *Intuitions in NE-RE: moral wisdom in the balance*

The confrontation with a moral case generally invokes spontaneous moral judgements that give the holder a preliminary sense of the direction in which a judgement about the case should go, elicited without awareness of underlying mental processes (Musschanga, 2008; Haidt, 2001). This preliminary judgement is what we refer to when we speak of 'moral intuitions'. These intuitions can be both pre-reflective and post-reflective. Pre-reflective interpretation occurs when a person is confronted with a moral situation he is unfamiliar with. In other cases the interpretation of a person is based on structuring of facts in previous cases and in this way influenced by *experienced perception*. This is called post-reflective interpretation (Haidt, 2001). Moral intuitions are relevant to ethical judgement, first, because they are usually the starting point of deliberation. Second, when a person comes to hold a moral intuition, he will generally feel the urge to look closer at the case and seek alternative interpretations of the circumstances (Willegenburg, 1991). Finally, moral intuitions connect ethical reflection to our everyday moral experiences.

A major objection against incorporating intuitions into moral reasoning is that it poses the risk of constructing a moral theory which, in fact, is nothing more than a systematisation of a person's subjective and biased judgements (Daniels, 1979; Strong, 2010). More specifically, the criticism entails the following: if justification of the result of an RE process is based on coherence of a set of beliefs, each of these beliefs has to be reliable enough to guide the process of reasoning. Moral intuitions, it is argued, are subjective and can be erroneous. Therefore, they lack the credibility that is necessary to add to the justification of judgements in a coherentist model of moral reasoning like RE. To defeat the no-credibility objection, some authors suggest stringent selection of initial judgements at the start of reasoning, in order to prevent the 'bad' ones from entering the reasoning process (Swanton, 1991; Neilson, 1982; Singer, 2005). For example, Beauchamp and Childress (2013) argue for the use of the *common morality* as a reliable source of moral intuitions that can be allowed into the reasoning process.

In NE-RE, we propose a different approach to correct for the problem of subjectivism and conservatism in RE. We follow DePaul in his claim that a justifiable outcome of moral deliberation in RE is not dependent on the general credence levels of the elements *at the start* of the reasoning process (DePaul, 1993; Theil & Delden, 2009). The justificatory power of a moral view resulting from NE-RE depends largely on the quality of the reasoning process. Therefore, the focus in NE-RE is on the strength of the arguments put forward in the process of reasoning towards coherence. In addition, we propose to broaden the set of relevant intuitions, using empirical research, to include the moral intuitions of persons other than the thinker (Theil & Delden, 2009). Since it is likely that the moral judgements of people, who work and live in a certain practice, are usually at an intuitive level, it is

through these intuitions that moral theorising can gain access to a moral experience that generally cannot be found among people outside the health care practice. In our analysis of Ashley's case we obtained unexpected insights, descriptions of experience, and interpretation from different perspectives or angles in an empirical study. The value of such an 'encounter with experience' has been described by others as well (Ives et al, 2008).

### *Measuring coherence and knowing when you have enough*

The coherence among beliefs is essential for justification of a moral view attained through NE-RE. This, however, poses two challenges for NE-RE. First, the nature of coherence, and the way people should evaluate their beliefs with respect to coherence, is poorly described (Beauchamp & Childress, 2013; DeGrazia, 2003; Rauprich, 2008). In NE-RE we propose to use the notion of *inference relations* to analyse different types of coherence in a given set of beliefs. We look closer at the type of coherence that is present (or absent) among beliefs. In working towards coherence among beliefs regarding Ashley's treatment, we outline the practical use of these ideas on measuring coherence.

Second, it is unclear *how much* coherence is necessary to decide that the point of reflective equilibrium is reached (Petersson, 1998). Mere absence of contradiction is unlikely to be sufficient for a set of beliefs to qualify as a reflective equilibrium. Hence, minimal coherence should not be pursued at the cost of a comprehensive result. Connectedness among beliefs is essential to arrive at a convincing RE (Sayre-McCord, 1996). These considerations give some guidance, but clearly do not answer the question of how much coherence is enough. For NE-RE, we explored the idea of *Coherentism with different levels of justificatory power* (van Theil, 2009). This is based on the claim that the degree of justification of a single belief can vary due to factors other than coherence – understood as the inference relations between that belief and the other beliefs in the set. For example, some beliefs may have a distinguished initial status, and this can confer a certain weight on a belief. Durability is an example of a weighing-factor: we are likely to have more confidence in judgements that are confirmed in a history of cases. Assessment of the relative weight of elements in a RE can help to evaluate the justificatory power of the view achieved through NE-RE.

### **Hands on: NE-RE in the case of Ashley X**

Usually, reasoning in (NE-)RE starts with a number of considered moral judgements or moral intuitions. In the Ashley case, we started to work towards RE with a search for intuitions of other people to enrich our set of initial moral beliefs.

### *Qualitative empirical research: methods and results*

We chose Internet Message Boards that were opened for discussion shortly after the Ashley Treatment was made public. On 18 January 2007 – 3 months after publication – we entered the query 'discussion on growth attenuation Ashley' into Google. It returned 40.600 hits. We chose three message boards as a source of data. First, we picked the one with the largest number of postings: MSNBC Message Board (2008) *Kids and Parenting: All in the family* (2334 messages). Secondly, we chose *Have your Say* (BBC, 2008). The 497 messages on this board were from people who reported to come from one of over 30 countries. Finally, we selected the message board of *Ouch!* (2014), a website that aims to reflect the lives of disabled people.

We extracted 438 pieces of text from a total of 3004 postings. Three criteria guided the selection: (1) the text comprised an interpretation of the case, (2) the writer expressed a judgement in terms of right, wrong, acceptable, praiseworthy etc. and (3) the text was not a lengthy and well-thought out discussion of the case. By applying these criteria we expected to extract moral intuitions from the contributions. Subsequently, we assigned one or more labels to each piece of text. After labelling 339 text pieces, we decided the point of saturation was reached because we had not added new labels for a while and it seemed unlikely new labels would be added. The results are shown in Table 1.

### *Confront empirically found intuitions with moral principles*

The qualitative research provided us with a set of initial moral beliefs (Table 1). The next step in RE is to confront moral intuitions with moral principles. In theory, these can be new principles, but it is likely that a thinker will come up with at least some of our commonsensical moral principles (i.e. keep promises, respect autonomous choices) (Arras, 2007). The confrontation entails a reflective process, in which intuitions and principles are considered together. In this process, principles can be abandoned, revised or restated and intuitions can lose or gain credibility based on their coherence with the principles. In the Ashley case, we considered the principles of (respect for) autonomy, beneficence, non-maleficence and (respect for) human dignity and confronted them with the moral intuitions.

#### Autonomy

Many commentators on the internet hold intuitions that refer to the question: who has the right to decide about Ashley? We came across moral intuitions that emphasise the right of the surrogates with respect to decision making (for example, table 1:P6,P7). Others wrote that the parents are responsible for the care and they have demonstrated that they live up to what society expects from loving parents (P8). The principle of respect for patient autonomy demands that we refrain from interfering with an autonomous person's right to live his life according to personal values and beliefs. Ashley is not competent to give valid consent regarding the treatment planned for her. It is beyond question that the parents are the legal representatives of their daughter. The fact that they are Ashley's loving caregivers adds significance to their preferences.

On the other hand, the parent's rights are limited by their duty to protect Ashley's interests (C8). Some commentators point at the responsibility of society as a whole to defend the vulnerable if their representatives fail to do so (C16). This raises the question of according to which standard(s) the parents should make their decision.

*Substituted judgement* is usually a guiding principle in these cases, and it would mean that Ashley's parents should choose the course of action that Ashley herself would have chosen if she was competent (C14). However, substituted decision making in this case is hampered because the decision makers do not have a single lead regarding the choices Ashley, or more generally people in her position, would make (Beauchamp & Childress, 2013). In the absence of reliable traces of a person's wishes, surrogate decision makers should decide in accordance with the *best interest standard*. This calls for an evaluation of the burdens and benefits of the treatment.

#### **PRO: Moral intuitions positive about the Ashley treatment**

- P1 The treatment is ethical because the parents acted with the intention to help, not to harm.
- P2 The burden on Ashley's parents should be lifted as much as possible. This justifies the treatment.
- P3 This is an ethical way of balancing the needs of the different parties in the family
- P4 The treatment is right. It adds to Ashley's quality of life because she will be better cared for.
- P5 This is in Ashley's best interest because people will respond to her better when she is a child.
- P6 The parents have the right to choose medical treatment for their daughter.
- P7 If society does not assist the parents in caring for Ashley, they should be free to take the measures necessary to care for her.



- P8 The parents show to be responsible parents by taking care of her. This should be rewarded
- P9 Parents and doctors are in the best position to decide what is good for Ashley
- P10 Nothing meaningful is taken away from Ashley by this treatment.
- P11 The treatment is right because it avoids harm (menstruation, bed sores, sexual abuse, etc)
- P12 This is acceptable because the alternative for treatment – Ashley being cared for outside the home – is worse.
- P13 Corrective surgery is elected by many people and thus not unethical in this case
- P14 The doctors and parents proceeded carefully and are backed by an ethics committee. This is enough for justification
- P15 Medical treatment is used for the good of people – that's what happened here

#### **CONTRA: Moral intuitions negative about the Ashley treatment**

- C1 This is wrong because the motivation of the parents is selfish convenience.
- C2 There were no convincing medical grounds for the surgeries, this makes them therefore unethical.
- C3 The treatment is disrespectful and a violation of Ashley's rights as a person.
- C4 The treatment denies Ashley valuable experiences that come with adulthood.
- C5 This sets a precedent to perform medically unnecessary treatment to other non-consenting persons
- C6 This is wrong because it is unnatural
- C7 We cannot rule out that Ashley might develop different than expected. Irreversible treatment is thus wrong. The family and doctors have now chosen her development.
- C8 Some decisions are not at our freedom to make. No matter the reasons we have.
- C9 The parents should either take on the responsibility to care for Ashley or let others do it.
- C10 The treatment is based on the paternalistic and false assumption that disabled people will benefit from imitation of 'normality'.
- C11 This is an example of going way too far to keep disabled people alive. She should be left to die.
- C12 The treatment is unethical because there are less invasive options
- C13 Ashley should not be altered to meet the needs of society or her carers. Society and the carers need to change to meet the needs of people
- C14 No one would choose this treatment for herself, and that is reason enough not to put Ashley through it.
- C15 This is mutilation!
- C16 Society should defend the vulnerable
- C17 This is a waste of resources
- C18 They are experimenting on this girl just to stir the debate

Table 1: Moral intuitions regarding The Ashley Treatment

### Beneficence

We came across the moral intuition that the *intention* of the parents and physicians is decisive for a positive evaluation of the Ashley Treatment (P1). Since the key question in this case is whether the parents made a wrong decision in spite of their good intentions, we decided to set aside this intuition.

Many commentators in favour of the Ashley treatment frame it as a good thing for Ashley, because it promotes her well-being (P4,P5). The principle of beneficence refers to a moral obligation to help others further their important and legitimate interests (Beauchamp & Childress, 2013). Growing into adulthood is said to be one of the major obstacles to family care for Ashley. This claim is added to the belief that all children, regardless of the presence of a disability, belong in families (Gunther & Diekema, 2006). Considering the amount of care Ashley needs, it seems plausible that she will benefit if the burdens of care are lifted as much as possible (P2). Moreover, the parents may be able to care for Ashley at home for a longer period of time when she remains of 'manageable size' – as her doctors put it. The treatment may prevent harms like bedsores and spasms (P11). This benefit could remain even if Ashley would be cared for in a different setting.

### Non-maleficence

The principle of non-maleficence draws attention to two questions, namely:

- (1) Are the risks and burdens involved in the treatment proportionate in the light of expected benefits?
- (2) Is the least harmful option chosen to achieve the benefits

It seems realistic to assume that the necessary caring activities will be performed more easily, better or more often when Ashley's body remains small. Considering Ashley's mental capacities, it is unknown, but unlikely, that she will have negative experiences related to her abnormal physical development. The surgical part of the Ashley treatment serves additional purposes. These were justified partly by arguing for the need to "reduce the long-term complications of puberty in general and treatment adverse effects in particular" (Gunther & Diekema, 2006:1014). Regarding breast-development, the parents stated that Ashley might suffer from discomfort and that large breasts could 'sexualize' her and make her more vulnerable to abuse by (future) caregivers from outside the home. On an intuitive level, we may believe that Ashley is not harmed if she remains small and child-like (P10). On the other hand, we hold the moral intuition that there is something morally meaningful to the fact that the manipulation of Ashley's physical appearance seems to have gone beyond what is necessary to achieve the benefits for her care. For further exploration of this intuition, we turn to the principle of respect for human dignity.

### Respect for human dignity

To grasp the meaning of dignity in the light of our moral intuitions regarding the treatment of Ashley, we point at two notions of dignity – unconditional dignity and dignity as moral stature (Graf, 2009; Nordenfelt, 2004). Unconditional dignity is embedded in the nature of all human beings, regardless of their achievements or the condition they are in. Unconditional dignity can be violated, for example when a human is being treated as non-human, like an animal or a thing. In Ashley's case the intuition was articulated that the treatment is disrespectful and a violation of Ashley's rights as a person (C3). The treatment is considered 'unnatural' and 'experimenting', or as an unacceptable way of 'taking care' (C6, C18, C9). The second notion, of dignity as moral stature, is applicable to the caregiver's position. Van der Graaf calls this type of dignity 'relational': it can be gained by performing well in relation to others. Ashley cannot protect herself against violations of dignity and this bestows upon her

caregivers a more than average responsibility to uphold a certain moral standard. In this case, it could be argued that altering Ashley's body and preventing her 'natural development' is something that dignified caregivers would not opt for (C7). Some commentators hold the view that the parents must have been driven by selfish convenience, which is also contrary to dignified parenting (C1). The idea that the treatment may be a violation of dignity is fuelled by the fact that the parents seem to be doing more than just facilitating optimal care for the benefit of their child. The desire to 'desexualize' Ashley affirms especially the presumption that the parent's aspirations reached further than facilitating home-based care. Regarding the justification of these aspirations, there is no evidence that having the physical appearance of a child is beneficial *to Ashley*. It is possible that people in general respond better to mentally handicapped children than to adults with the same disability. But will Ashley actually *experience* the difference? If not, changing her appearance serves to make people other than Ashley more comfortable. Medical treatment of a non-consenting person to meet our own needs is a violation of unconditional dignity. It is also an infringement on the moral stature of her parents and doctors as dignified caregivers.

At the start of our reasoning we found a variety of intuitions and principles. We confronted these with each other and tried to adjust and interpret them with the aim to fit them into a comprehensive and coherent view on the case.

### *Second round of reasoning: background theories and moral ideals*

After confronting intuitions with principles, and vice versa, we introduce background theories and moral ideals in a second round of reasoning. The purpose of involving background theories is to reduce the risk of subjectivism through evaluation of the acceptability of moral intuitions and principles from an independent source (St John, 2007). This is termed the 'independence constraint'. Currently, more specific guidance on criteria for selection that allow the Thinker to defend his choice of background theories against critics is lacking. To choose relevant background theories in the Ashley case, we considered the fact that our confrontation of intuitions and principles resulted in the preliminary view that the growth attenuation is ethically defensible but the surgical treatments are not. The difference in ethical evaluation is based on the assumption that the arguments legitimate a *medical* intervention that influences Ashley's growth. However, the argument for surgical treatment to prevent menstruation and breast-development is, in our view, not sufficiently justified. The relevant question here is whether or not, in Ashley's case, it was appropriate to look for options from the realm of medicine to relieve care. In other words: was a *medical* intervention indicated or were non-medical – emotional or social – problems or solutions decisive in this case? These questions touch upon more general theories about the goals of medicine. Therefore, to critically evaluate our preliminary view on the Ashley treatment, we chose to bring general views on health, disease and the role of medicine into the reasoning process.

#### Was Ashley medically treated for a disease?

Some authors suggest that the goals of medicine are multidimensional and include promoting quality of life and increasing the length of life (Brulde, 2001). However, *health* is still taken to be the central goal in medicine (Nordenfelt, 2007). If the goal of medicine is health, then the concepts of health and disease mark off legitimate medical practices from illegitimate variants. This demarcation is exactly what we need in our normative discussion on the Ashley treatment. Generally speaking, there are two competing theories of health. The first one is Boorse's Biostatistical Theory of Health. A person is healthy if all his organs make at least their statistically normal contribution to his survival or to the survival of the species to which he belongs. A diseased person has a dysfunction that can be detected by medical methods. Second is the Holistic Theory of Health. A person is healthy if he has the ability to reach vital goals for minimal happiness. These goals, are on the one hand, influenced by historical developments and, on the other hand, individually relative (Khushf, 2007). The biostatistical theory of health leads us to recognise the fact that, regardless of possible benefits, it is disturbing that the healthy functions of Ashley – such as her bodily growth and development – were not protected or

restored, but are now abnormal due to medical intervention. The holistic concept of health leads us towards accepting that patients are allowed to bring values other than physical functioning into the medical arena. This view fits our preliminary conclusion, that the growth attenuation is likely to help achieve a legitimate goal. The parental worries about menstruation and sexual abuse may have been inspired by fear of Ashley becoming an adult or by the fact that the parents realise that someone in Ashley's condition is extremely vulnerable. In arguing for the necessity of these interventions, parents and physicians seem to move away from what we can reasonably assume is valuable to Ashley. And by doing this they leave the realm of legitimate medical practice.

### **Towards reflective equilibrium: examining the level of coherence**

The final step in the practical application of NE-RE is thorough analysis of all connections in the set of beliefs we identified in the Ashley case to assess the justificatory power of the set of beliefs now considered to be in equilibrium. In this chapter, we limit our assessment to a rather quick-and-dirty inspection of inference relations between the beliefs, to give the reader a sense of how a Thinker can proceed.

#### *Strong positive inference relations*

We can roughly distinguish three strong positive connections that determine the moral view we endorse after analysis of the Ashley treatment through NE-RE:

##### *(i) Growth attenuation and good care (beneficence)*

We found positive inference relations between the growth attenuation and the aim of providing Ashley with the best care. Thus, there is coherence between the action of growth attenuation and the goal of good care.

##### *(ii) Growth attenuation and the obligation to choose the least invasive option to achieve good care.*

The principle of doing no harm requires that the least invasive option is chosen to achieve the goal of caring for Ashley. Growth attenuation can be seen as no more invasive than other measures to sustain good care, such as hoists and institution-based care. This judgement positively connects with the principle, and in doing so constitutes coherence among these beliefs.

##### *(iii) Growth attenuation and the goal of promoting well-being*

We compared the reasons for growth attenuation in the Ashley case with accepted indications for this treatment. An argument in favour of the Ashley treatment is based on the analogy between Ashley and tall adolescent girls who wish to minimize any further gain in height for social or cosmetic reasons.

#### *Weak positive inference relations*

Besides the strong connections, we see several positive relations that add to the overall coherence, but are less convincing on their own.

##### *(i) Surgical treatment and the obligation to choose the least invasive intervention for prevention of complications of puberty*

The connection between the surgical treatment and this obligation is much weaker, for two reasons. First, the *complications of puberty* remain vague and second, less invasive options seem available.

##### *(ii) The Ashley treatment and the goal of medicine to promote vital goals for Ashley's happiness*

We analysed different views on the goals of medicine in working towards wide reflective equilibrium. According to a holistic view, we can identify a positive connection between this treatment and the value of providing loving care for Ashley.

#### *Negative inference relations*

Considering our set of beliefs, we see at least three negative connections.

##### *(i) Surgical treatment and the prevention of harm (as in sexual abuse)*

The surgical treatment was defended by Ashley's parents by referring to the risk of sexual abuse. However, there is no evidence that the surgical treatment will prevent the harm. Thus, this connection is not producing coherence.

##### *(ii) The Ashley treatment and the goal of medicine to protect and restore health*

The central goal in medicine is health. There is a negative connection between this goal of medicine and the Ashley Treatment, due to the fact that Ashley's healthy functions were hampered. Our negative judgment about the surgical treatment coheres with the principle of non-maleficence.

##### *(iii) Respect for human dignity and the Ashley treatment*

The Ashley treatment goes beyond influencing Ashley's body-size towards manipulation of her whole appearance. It is questionable if this is beneficial to Ashley. This weakens coherence between the principle of respect for human dignity and a positive judgement about the Ashley treatment.

#### **Discussion: ethical analysis of the Ashley case through ne-re**

The model of NE-RE allows us to combine empirical and normative elements in ethical decision making. Our inventory of arguments for and against the Ashley Treatment may raise the question of whether this empirical work adds significantly to the set of beliefs/intuitions that were considered. Can an individual Thinker come up with these beliefs without the investigation? This is an empirical question, which is difficult to answer without experiment. However, in the academic debate, the moral significance of the distinction between the growth-attenuation part of the treatment and the surgical part surfaced, but was not explored further (Stein, 2010). In addition, those in favour of the treatment, decided not to focus on the surgical part without much argument (Allen et al, 2009; Diekema & Fost, 2010; Wilfond et al, 2010). These arguments may not have been dismissed so easily when the moral intuitions pointing at a relevant distinction were assigned equal prima facie status as other relevant beliefs.

Another issue is the choice of the background theories. We chose to analyse the moral intuitions and principles from the perspective of a theory of health and medicine. However, it may be argued that a theory of social responsibility or personhood should have been explored instead. For example Brosco (2006) and Feder Kittay (2011) refer to the social model of disability and a care ethic respectively, and convincingly show the relevance of this perspective for the moral evaluation of the Ashley Treatment. RE (and NE-RE) does not provide guidance in the choice of elements. A different result may be produced by another Thinker, and this has been recognised as a weakness of (NE-)RE (Knight, 2006; Strong, 2010).

Our use of NE-RE for normative analysis of the Ashley Treatment may serve as an example of the application of RE, which can be used by others when considering different moral issue. The example may also stimulate further critical discussion of NE-RE, which can be the starting point of improvement of the model itself.

## References

- Allen DB, Kappy M, Diekema D, Fost N. Growth-attenuation therapy: principles for practice. *Pediatrics* 2009;123(6):1556-1561.
- Arras JD. The way we reason now: reflective equilibrium in bioethics. In Steinbeck B (ed.). *The Oxford handbook of bioethics*. New York: Oxford University Press, 2007.
- Anon. The method in bioethics research. *Kennedy Inst Ethics J* 2007;17:277-278
- BBC. 2008.  
<http://newsforums.bbc.co.uk/nol/thread.jspa?sortBy=1&threadID=5141&start=75&tstart=0&edition=2&ttl=20070110125922&#paginator> [Accessed 16 April 2008].
- BBC. 2014. [bbc.co.uk/dna/mbouch/F2322273?thread=3779612](http://bbc.co.uk/dna/mbouch/F2322273?thread=3779612) [Accessed 03 February 2014].
- Beauchamp T and JF Childress. *Principles of Biomedical Ethics*. 7th ed. New York: Oxford University Press, 2013.
- Brosco J. Growth Attenuation: A diminutive solution to a daunting problem. *Arch Pediatric & Adolescent Medicine* 2006; 160(10):1077-78
- Brulde B. The goals of medicine: towards a unified theory. *Health Care Analysis* 2001;9:1-13.
- Daniels N. Wide Reflective Equilibrium and Theory Acceptance in Ethics. *J Philos* 1979;76:256-282.
- DeGrazia D. Common Morality, Coherence and the Principles of Biomedical Ethics. *Kennedy Inst Ethics J* 2003;13:219-230
- Diekema D, Fost N. Ashley Revisited: a response to the critics. *The American Journal of Bioethics* 2010; 10(1):30-44.
- Delden J van, Thiel G van. Reflective Equilibrium as a Normative-Empirical Model in Bioethics. In: W van der Burg and T van Willigenburg (eds.) *Reflective Equilibrium*. Dordrecht: Kluwer Academic Publishers, 1998: 251-259.
- DePaul MR. Balance and Refinement. *Beyond Coherence Methods in Moral Inquiry*. London/New York: Routledge, 1993:145-146
- Feder Kittay E. Forever small: the strange case of Ashley X. *Hypatia* 2011;26(3):610-630.
- Graaf R van der . Clarifying appeals to dignity in medical ethics from a historical perspective. *Bioethics* 2009 Mar;23(3):151-60.
- Guardian. 2014. [www.theguardian.com/society/2012/mar/15/ashley-treatment-rise-amid-concerns/print](http://www.theguardian.com/society/2012/mar/15/ashley-treatment-rise-amid-concerns/print) [Accessed 16 October 2014]
- Gunther DF, Diekema DS. Attenuating growth in children with profound developmental disability. *Archives of Pediatric and Adolescent Medicine* 2006;160(10):1013-1017.
- Haidt J. The emotional dog and its rational tail: a social intuitionist approach to moral judgment. *Psychology Review* 2001;108(4):814-834.
- Isaacs DA, Tobin BC, Hamblin JD, Slaytor ED, Donaghue KCB, Munns CB, Kilham HAAC. Managing ethically questionable parental requests: Growth suppression and manipulation of puberty (Review). *Journal of Paediatrics and Child Health* 2011; 47(9): 581-584
- Ives J, Draper H, Pattinson H, Williams C. Becoming a father/refusing fatherhood: an empirical bioethics approach to paternal responsibilities and rights. *Clinical Ethics* 2008; 3(2):75-84.

- Ives J, Draper H. Appropriate methodologies for empirical bioethics: it's all relative. *Bioethics* 2009;23:249-258.
- Ives J. A method of reflexive balancing in a pragmatic, interdisciplinary and reflexive bioethics. *Bioethics* 2014;28(6):302-312
- Khushf, G. 2007. An agenda for future debate on concepts of health and disease. *Medicine, Health Care and Philosophy* 10:19-27
- Knight, C. The Method of Reflective Equilibrium: Wide, Radical, Fallible, Plausible. *Philosophical Papers* 2006; 35(2):205-229
- MSNBC Message Board. 2008.  
<http://boards.msn.com/MSNBCboards/thread.aspx?BoardID=762&ThreadID=115796&BoardsParam=HIPDelay%3d1> [Accessed 16 April 2008].
- MSNBC Message Board. 2007. Message #1861 MSNBC Message Board, posted 01/06/07 11:02 PM.  
<http://boards.msn.com/MSNBCboards/thread.aspx?BoardID=762&ThreadID=115796&BoardsParam=HIPDelay%3d1> [Accessed 16 April 2008].
- Musschenga AW. Moral judgement and moral reasoning: a critique of Jonathan Haidt. In: Düwell M et al. (eds.). *The contingent nature of life. Bioethics and the limits of human existence*. Dordrecht: Springer 2008:131-147.
- Nielsen K. Grounding rights and a method of reflective equilibrium. *Inquiry* 1982;25:277-306.
- Nordenfelt N. The varieties of dignity. *Health Care Anal* 2004; 12:69-81
- Nordenfelt. The concepts of health and illness revisited. *Medicine, Health Care and Philosophy* 2007;10:5-10.
- Petersson B. Wide reflective equilibrium and the justification of moral theory. In: Burg W van der, Willigenburg T (eds.). *Reflective Equilibrium*. Dordrecht: Kluwer Academic Publishers, 1998:132.
- Rauprich O. Common morality: comment on Beauchamp and Childress. *Theor Med Bioeth* 2008;29:43-71.
- Pillow Angel. 2014. [www.pillowangel.org](http://www.pillowangel.org) [Accessed 3 February 2014].
- Rawls J. *A Theory of Justice*. Cambridge: Harvard University Press, 1971; revised edition 1999:xiii.
- Sayre-McCord G. Coherentist Epistemology and Moral Theory. In: Sinnott-Armstrong W, Timmons M (eds). *Moral Knowledge? New Readings in Moral Epistemology*. New York/Oxford: Oxford University Press, 1996:137-189.
- Singer P. Ethics and Intuitions. *J Ethics* 2005;9:331-352.
- Stein GJ. Ashley's case: the ethics of arresting growth of children with serious disability. *Journal of Social Work in Disability and Rehabilitation* 2010;9:99-109
- St John J. Problems with theory, problems with practice: wide reflective equilibrium and bioethics. *S Afr J Philos* 2007;26:204-215.
- Strong C. Theoretical and practical problems with wide reflective equilibrium in bioethics. *Theor Med Bioeth* 2010;31:123-140.
- Swanton C. The role played by the method of wide reflective equilibrium in moral epistemology. *Dialogue* 1991;30:575-589.

Thiel G van. Moral wisdom in the balance. Reflective equilibrium as a normative empirical model for bioethics. Thesis Utrecht University, Utrecht: 2009.

Thiel G van, Delden J van. The justificatory power of moral experience. *Journal of Medical Ethics* 2009;35:234-237.

Thiel G van, Delden J van. Reflective Equilibrium as a Normative Empirical Model. *Ethical Perspectives* (2010);17(2):183-202

Willigenburg T van. Inside the ethical expert. Kampen: Kok Pharos 1991:191.

Wilfond BS, Miller PS, Korfiatis C, Diekema DS, Dudzinski DM, Goering S. Navigating Growth Attenuation in Children with profound disabilities. *Hastings Center Report* 2010;40(6):27-40.



# Theory and Practice of Democratic Deliberation in Bioethics Research\*

Scott Kim

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Should we allow family members to make research participation decisions for their incapacitated loved ones when the research involves invasive procedures? (Kim 2011) How should we determine what are 'essential health benefits' for insurance plans? (Institute of Medicine, 2011) How should we balance the promise of emerging technologies—such as synthetic biology—with the risks of malicious use or unintended consequences? Like most policy issues, such questions cannot be answered solely by arm-chair reasoning. Yet given the *ethical* nature of the problems, one might hope for more than the usual special interest politics to settle the matter. Such policy debates should at least be informed by the moral views of the public. But eliciting informed and well-considered moral opinions of the lay public can be challenging. The issues may not be widely familiar and they may involve complex scientific, legal, historical, and ethical dimensions. Traditional surveys risk eliciting superficial and uninformed opinions that may be of dubious quality.

This chapter describes how the theory and practice of deliberative democracy (DD) is especially useful in such situations. The first section provides a theoretical rationale for why DD is especially suited to inform bioethics policy questions, with a brief overview of how DD is being used in bioethics. The second section is a practical, detailed guide to conducting DD research in bioethics. There are many varieties of DD methods, and it is impossible to describe them all. Thus, a detailed case study is presented to illustrate the broad principles of DD; this will provide the reader with a sense of how to adapt such methods to her own specific needs. The final section discusses some potential pitfalls of deliberations and how they can be avoided.

## Bioethics and Democratic Deliberation as Natural Allies

### *Democratic Deliberation: The Rationale*

How policies in fact are made is a large and complex topic (Kingdon 2002) and this is reflected in the fact that DD has been used to inform policy in various ways. Some DD studies are initiated and implemented by government agencies. For example, between 2001 and 2005, the Minister of Planning and Infrastructure in Western Australia used DD methods to directly inform policy-making through almost 40 deliberative engagements with the public (Gregory et al, 2008). At the other end of the spectrum are methods designed to elicit views of citizens that can be used to *inform* policy discussions, in a consultative model, with no involvement at all by a policy developing entity. In this chapter, I shall assume a consultative model of DD in which a researcher's goal is to provide an independent assessment, by means of normative opinion surveys—that is, surveys of the public's considered moral judgment about a bioethics issue. But how should the public's moral opinions be sought? How can we be sure that the opinions, elicited via surveys, are considered moral judgments of the public?

The methodological issues fall under two broad but interacting domains. First, how can we be sure that such surveys are based on the respondents receiving accurate, unbiased, and reasonably comprehensive information? Second, how can we be sure that the ethical opinions elicited are in some robust sense 'considered' opinions? Since most laypersons may not be familiar with a given ethical issue—or be familiar only with public information generated by partisan interest groups—and given the human tendency to seek information that affirms preconceived intuitions, rather than the

more difficult work of keeping one's mind open and challenging one's own views (Haidt, 2012), the respondents will need a chance to engage in a process that helps them develop, examine, and challenge their views. Ideally, this should be an interpersonal process that involves consultation with experts representing diverse viewpoints and deliberations with peers in a setting that promotes careful, considered, and civil dialogue.

This is a tall order for a researcher who seeks to conduct normative opinion surveys in bioethics. The amount of work needed to satisfy the above criteria will vary depending on the topic. For some issues, perhaps the media have done a reasonable job of educating the public and the issues are familiar enough so that most citizens are exposed to an adequate range of arguments regarding the issue. But for most issues in bioethics, meeting those criteria will be difficult. Over the past few decades, political philosophers and political scientists have developed theories of *deliberative democracy* (DD), an approach to incorporating public opinion in policy-making (Chambers, 2003). These scholars, together with policy researchers and citizen activists, have been using a variety of empirical methods to engage the public on various policy issues (Carson et al., 2005; Gastil & Keith 2005; Fishkin, 1997; Thompson, 2008).

Although the boundaries and definition of DD are not always clear, what is common to all theories of DD is the idea that informed and deliberative input of citizens is seen as the ideal for democratic governance (Bohman & Rehg, 1997). This deliberative input is more than simply summing up or aggregating opinions in some coordinated fashion. Some DD theorists, for example, argue for an ideal of reciprocal justification. As Gutmann & Thompson (1997) note in one of the earliest attempts to delineate the implications of DD for bioethics, DD theory asks "citizens and officials to justify any demands for collective action by giving reasons that can be accepted by those who are bound by the action" (pp38).

On the surface, deliberative democratic ideals seem to embody a fairly non-controversial vision of citizen participation in the political process. But the popularity of deliberative democratic theory in political science and philosophy is a relatively recent phenomenon. As Bohman & Rehg (1997) note, during the middle of the 20<sup>th</sup> century, the dominant theories of democracy tended to be suspicious of public deliberation and saw reason as instrumental, as a tool for gaining the upper hand in interest group politics, as a tool in bargaining with opponents, or as a means of aggregating preferences most efficiently. In contrast, deliberative democratic theory is a normative theory that takes citizens' views seriously in informing policy. Much of the philosophical literature on DD is devoted to working out the essential elements and critiques of this core idea of citizen deliberation as the basis of governance (Bohman & Rehg, 1997; Elster, 1998; Freeman, 2000; Chambers, 2003). Deliberative democratic theory is more optimistic about the idea that citizens can deliberate and reason together and come to share a *common* good, at least to some degree.

### *Deliberative Democracy and Bioethics*

It is not hard to see why DD theories have important implications for bioethics. Such theories provide a broad theoretical framework for what is implicitly accepted within bioethics. How should our public policy regarding controversial bioethics issues be resolved? One approach is to provide some background rules (no violence, no fraud, etc.) but allow the flow of money and influence to determine the outcome, without an attempt to promote a 'common good' perspective. Let the stronger interest groups win, as long as they play by a set of rules. Alternatively, we could attempt to resolve the conflict by promoting a deliberation among citizens during which an attempt is made to find a common perspective. The possibility that people can change their minds based on giving reasons and evaluating others' reasons is left open.<sup>66</sup> Such a perspective would respect the citizens' abilities to consider tradeoffs necessary in public policy, rather than assuming that they will only protect their own personal interests. The interaction is not just for purposes of influence; people treat one another as decision-makers who deserve respect by being provided with reasons that they can evaluate and respond to.

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<sup>66</sup> See Sheehan (2016) and Landeweer et al (2016), both in this volume, for two different perspectives on this question.

It would be discouraging if policy solutions to modern bioethics dilemmas were addressed only by means of special interest group politics, or based only on economic considerations or other forms of power. If this were the normatively accepted way of resolving ethics policy problems, it is hard to see why such problems would be considered 'ethical' problems at all. This concern has been implicitly recognised in that, historically, the usual mode of addressing bioethics issues has been to turn to expert panels and commissions (Jonsen, 1998). These commissions have been hugely influential, with much of the current U.S. human subject research regulations, for example, being a product of one of those commissions (Levine, 1986). These commissions do embody some key components of DD, in so far as they publicly deliberate, attempt to incorporate diverse and opposing viewpoints, are led by evaluation of reasons and arguments, and, to a limited degree, represent an interdisciplinary perspective, including representatives from the public or from patient advocacy groups. But panels are limited in that they draw on the moral intuitions of a few and it is not clear whether they reflect the moral views of the public. Also, it is important not to confuse DD with representation by layperson groups, such as patient advocacy groups. Political action by advocacy groups is an essential part of our democratic system. But they are operating as an interest group. Thus, the inclusion of such groups in deliberations of ethics policy issues is not an automatic indication of *democratic* deliberation.

### *Practice of Deliberative Democracy*

Public deliberation has had a long and active history, quite apart from the theoretical developments in political philosophy (Gastil & Keith, 2005). There are now many models designed to implement deliberative democratic methods in policy-making. These models go by the name of Deliberative Polling (Fishkin, 1997), Citizens Jury (Crosby et al., 2005), 21<sup>st</sup> Century Town Meetings (Lukensmeyer et al., 2005), National Issues Forums (Melville et al., 2005), and others (Gastil & Kelshaw, 2000). Thus it is not correct to talk about *the* deliberative democratic method. Some have adapted and combined these methods, in attempts to improve public deliberative input into policy (Carson et al., 2005). In fact, there has been such a proliferation of empirical work in DD that there are now multiple reviews and theoretical reflections on the relationship between the theory and practice of DD (Chambers, 2003; Carpinì et al., 2004; Ryfe, 2005; Thompson, 2008), with a recent edition of a prominent bioethics journal featuring several articles on DD (Goold et al., 2012).

### *Deliberative Democracy Studies in Health Policy and Bioethics*

The area in bioethics that has used DD methods most actively is public priority setting and resource allocation. Between 1981 and 2006, 175 such articles reported on 190 public studies of public engagement conducted in the US, UK, Canada, Australia, and New Zealand (Mitton et al., 2009). Although not all involved deliberative methods, the authors note that "in each successive time period... the proportion of cases in which at least one deliberative method was employed increased," with 37% of studies involving deliberation by 2000-2006 period (Mitton et al., 2009; 224). More recently, a review of peer-reviewed articles from 2000-2012 on public deliberation of health policy or bioethics issues (restricted to papers with the words 'deliberation', 'deliberate', or 'deliberative' in title or abstract) yielded 31 papers published in 15 different medical, social science, and policy journals (Abelson et al., 2013). Quite recently, the Agency for Healthcare Research and Quality completed a demonstration project comparing four different deliberation methods and a control arm (Carman et al., 2013). They elicited public input on the use of research evidence to limit healthcare decision-making, and the methods ranged from a reading material only control group to a Citizen's Panel lasting 2.5 days.

DD methods are used in other areas of bioethics. As discussed below, DD methods have been used to address the dilemma of enrolling incapacitated adults in dementia research (Kim et al., 2010 & 2011). In compliance with the Federal regulations regarding emergency research without informed consent (21 CFR 50.24), a variety of methods have been used to meet the 'community consultation' requirement (Baren & Biros, 2007). Research with biobank samples or medical records are increasing the focus of public deliberation studies (Damschroder et al., 2007; Secko et al., 2009; Botkin et al., 2012). It is notable that the current Presidential Commission for the Study of Bioethical Issues in the U.S. is headed by one of the leading scholars of deliberative democracy, and their

reports have prominently endorsed democratic deliberation as a method for informing difficult bioethics policy issues (Gutmann, 2011).

## **A Case Study of Democratic Deliberation**

### *Ethics of Dementia Research: Appropriateness of the Topic for DD*

Dementia research requires participation of persons with significant cognitive impairment who may have difficulty providing informed consent (Kim et al., 2001, Okonkwo et al., 2007). Despite several decades of debate, there is as yet no uniform and clear legal policy regarding the involvement of decisionally impaired adults in clinical research in most jurisdictions of the US (Saks et al., 2008). Although US regulations allow research with incapacitated adults based on consent by their legally authorised representatives (LAR) (45CFR46, 102c, 111.a4, and 116), the regulations defer to states for defining the LAR and few states have done so (Hoffmann & Schwartz, 1998; Saks et al., 2008). Three states have modern laws on the issue (California, Virginia, and New Jersey) but have diverged on how to balance the potential benefits with risks (Saks et al., 2008). In the UK, there are three different regulations that may apply depending on the location and type of research involving persons with dementia (Nuffield Council on Bioethics, 2008). Given the absence of uniform and clear policy, Alzheimer disease research centers (Cahill & Wichman, 2000; Karlawish et al., 2002) and research ethics review boards (Bravo et al., 2010; Gong et al., 2010) vary significantly in their practices.

A DD method is well suited for this controversial topic. Prior to our DD work on this issue, all studies on this topic had been traditional surveys (Wendler et al., 2002; Bravo et al., 2003; Kim et al., 2005 & 2009; Karlawish et al., 2009). The topic involves several domains of specialised knowledge that need to be conveyed: the nature and purpose of scientific procedures in Alzheimer disease (AD) research, the rationale and structure of the current human subject protections system (including history of abuses, current oversight system through Research Ethics Committees, the ethical framework behind current regulations), the context of current AD research (the actual remaining capabilities of persons with moderate AD, the role of family members, etc.). It is a challenge to present all of the necessary background material in an understandable and comprehensive manner. Further, given that the topic is not a widely discussed issue among the public, it is unlikely that the public will have been exposed to the range of arguments for and against various policies.

Using the ethics of dementia research as a case study, the following sections discuss in depth several key methodological issues for a DD researcher in bioethics: rationale for an experimental design; development of study materials; procedures for the democratic deliberation session itself; necessity of facilitators; and monitoring and evaluation of the quality of the DD process.

### *Brief Overview of the Study*

Our study elicited the public's views regarding a policy for surrogate consent for four dementia research scenarios of varying risks and potential benefit: a lumbar puncture study to develop a diagnostic test, a randomized clinical trial of a drug, an efficacy study of a vaccine, and an early phase neurosurgical gene transfer study (Kim et al., 2013; Kim et al., 2011).

Participants were members of the general public aged 51 and older recruited via random digit dialing telephone calls within a 60 mile radius of Ann Arbor, Michigan. They were randomised into three arms: persons who completed surveys only (simulating a traditional survey, 'survey only group'), persons who received written educational materials about ethics and science of surrogate-based research (educational materials plus survey group, hereafter referred to as 'education group'), and persons who participated in an all-day democratic deliberation session ('DD session group').

There were three measurement time points: a survey sent to all participants one month prior to the DD session date (after which the subjects are randomised into the three arms); a second survey after the DD session for the DD group, or around that time by mail for the two control arms (survey only group and education group) who did not attend the DD session; a third survey to all groups by mail about one month after the DD session.

Participants assigned to the DD session group attended a day-long meeting that was comprised of plenary and small group sessions facilitated by trained facilitators. Two national experts (in AD research and in research ethics) presented detailed information, and were also available throughout the day, traveling together from table to table answering any questions.

### *Rationale for Experimental Design*

Because DD methods are relatively new to bioethics research it is important to assess whether a DD procedure has any impact at all on people's opinions. A randomised controlled experiment maximises internal validity, by accounting for any trends caused by factors extrinsic to the deliberation. The survey-only control group provided a traditional cross sectional survey comparison. The education group provided a comparison that sheds light on the mechanism for the impact of DD. That is, if the DD session does make a difference in the respondents' views, is it explained by the increase in information provided to the respondents or is deliberation also necessary? Given the cost and effort of DD sessions and the relatively novel use of DD in research ethics, we felt that adding this additional comparison group answered a valuable research question for relatively little additional expense.

Further, the experimental design maximised internal validity in a setting where the limitations to external validity are unavoidable. Although practitioners of deliberative consultation methods like ours cite generalisability as a strength (Fishkin & Luskin, 2005), it is important to recognise the limitations in sampling. DD methods require considerable time and effort from the participants—in our case, a full day of participation plus completion of several surveys. Setting aside an entire day for research involvement necessarily creates a certain level of selection bias. This is unavoidable as long as research relies on volunteers. However, by using a randomised design, we increase the rigor with which we can examine the impact of the DD intervention.

### *Development of Study Materials*

#### Video introduction to the DD day

An all day on-site session provides a unique opportunity to creatively inform and educate the participants. We provided a highly informative yet experientially driven background on Alzheimer's disease with a 30 minute segment of a critically acclaimed public television documentary, *The Forgetting: A Portrait of Alzheimer's* (Arledge, 2004). The segment was generated by discussing successive subsections of the film with 4 laypersons who had personal experience with AD (all of whom participated in a previous study we conducted).

#### Plenary Session Presentations.

The presentations on AD clinical research and on the ethics of surrogate consent for such research require extreme care to ensure that they are, in combination, balanced and fair. The integrity of the DD method depends on this. The presentations must also be audience-friendly and comprehensive enough for informed opinion formation, revision, or refinement. These presentations (slides plus notes) were first developed for an earlier DD study (Kim et al., 2010). The research team worked closely with an advisory panel that comprised a political science expert in deliberative democracy methods, a senior AD researcher, a bioethicist-sociologist, a geriatrician, a director of a human subject protections program at an academic medical center, a qualitative research expert, a gerontological nurse, and a caregiver of a person with AD. The penultimate versions of the presentations underwent a final systematic review by the advisory panel, additional external experts (in both AD research and bioethics) and laypersons.

#### Attitudes toward Surrogate-Based Research.

The survey was a shortened version of an earlier instrument that had been validated and used in a previous study (Kim et al., 2005). The survey elicits respondents' attitudes toward surrogate consent for dementia research, using 4 research scenarios of about 120 words each that depict a lumbar puncture study, a randomised clinical trial for a medication, a vaccine trial, and an early phase gene transfer trial.

### *DD Day Procedures*

Two weeks prior to the DD date, the members of the DD session group were provided with copies of the experts' presentations. Participants were asked to read through the presentations before the meeting, and to prepare any questions they have for the experts.

On the day of the DD session, DD group participants were randomly assigned to tables, in groups ranging from 5-7 persons per table, with the aim of having 6 participants per table, along with a facilitator. The sequence of events was designed to create an atmosphere of openness, respect, and collaboration within the groups (breaks and lunch are not listed below):

- Plenary Introduction that lays out the agenda for the day.
- First Small Group Session. Participants introduce themselves using an ice-breaker exercise. The facilitator explain his or her role. The video segment of *The Forgetting* documentary is presented and discussed.
- First Plenary Session. The audience is encouraged to ask questions during and immediately following each presentation.
  - Presentation on "Clinical Research in Alzheimer's Disease,"
  - Presentation on "Ethical Issues in Surrogate-Based Research."
- Second Small Group Session. Participants are given a chance to reflect upon and discuss the 2 plenary presentations. This allows for reactions and corrections to each other's understanding of the materials presented and to discuss the overall ethical dilemma of surrogate consent for dementia research.
- Second Plenary Session. Each research scenario (lumbar puncture study, new drug randomised clinical trial, vaccine study, gene transfer study) is discussed and the audience is given a chance to direct questions to the experts. This session is crucial because areas of incomplete understanding or concern shared by the audience will be brought out and interactively honed and corrects people's understanding of the issues.
- Third Small Group Session. By this time, the participants are quite comfortable with each other, have discussed the facts surrounding the issues, expressed their opinions and have had a chance to hear others' views *generally* about SBR. During this session, the participants are asked to answer as a group (for each research scenario), "If patients cannot make their own decisions about being in studies like this one, should our society allow or not allow their families to make the decision in their place?" The groups are also asked to provide their rationale: "Why should surrogate consent be allowed or not allowed?"

To maintain balanced, expert responses to all questions, the two experts (AD clinical researcher and bioethicist) are available and travel together from table to table to answer questions throughout the day. The extensive interactive component of the day minimizes the chance that the participants are basing their views on incorrect or incomplete information.

### *Key Role of Small Group Facilitators*

The entire DD procedure is based on the premise that optimal conditions must be provided to encourage rigorous, high quality deliberation over a controversial ethical issue. Although this could happen in the small groups by luck, having a facilitator ensures that the conditions for such deliberation are optimised. The trained facilitators optimize the process of discussion rather than act as content experts. Their training consists of two parts: one, a review of the facilitator's role, how to deal with difficult situations, and an annotated guide for the three small group deliberations; two, an in depth discussion and role play using scenarios collected from analyzing the previous DD small group

sessions. A pilot study can help develop various points that are potential problems and examples of particularly good facilitation.

Standardising the roles for facilitators is crucial to promoting good deliberation and minimizing unwanted group dynamic effects (Crosby et al., 2005). They must outline the ground rules for discussion, keep the group on task, promote respectful exchange of information, prompt clarification of statements, encourage expression of opposing viewpoints and participation by everyone, and limit domination of discussion by some participants.

At the same time, because laypersons naturally begin to defer to 'expert' opinion (Levine et al., 2005), the facilitators are reminded of this potential pitfall. Facilitators should not insert themselves into the discussion such that their opinion dictates the content of the group's outcome. The rule of thumb the facilitators are encouraged to keep in mind in determining whether to intervene in a particular situation is: Be neutral in content, but active in process.

### *Evaluating the Quality of Deliberations*

Do the participants of DD method actually engage in a reasonably high quality deliberation that is informed, thoughtful, and consisting of civil exchange of ideas? Since the validity of the outcome relies on DD fulfilling its promise, a DD study should monitor and report on the quality of the deliberation. These are not simple phenomena to measure, and a single approach is not sufficient (Steiner et al., 2004; Fishkin & Luskin, 2005; Neblo, 2007; Thompson, 2008).

We assessed quality in various ways (De Vries et al., 2010; De Vries et al., 2011). First, we assessed the participants' perceptions of civility and respect, fairness of the process, participant trust, and the value participants place on information and deliberation (Steiner et al., 2004; Thompson, 2008), using a self-report questionnaire administered at the end of the DD session day. Second, to assess the level of engagement and equality of participation (Cohen, 2007; Thompson, 2008), we tracked some simple metrics. The number and types of questions from the audience during the expert presentations and during small group deliberations provided a measure of active participation. We also recorded the number and length of times (text length) each participant speaks during small group deliberations. It is not necessary that everyone speaks the same number of times or for the same duration to ensure equality and good deliberation, but it is necessary that no one or two individual(s) *dominate(s)* the discussions and that everyone has the *opportunity* to speak their mind (Neblo, 2007).

Third, the small group deliberations are qualitatively analysed to address a variety of questions that touch on the quality of deliberation: How are disagreements resolved? Are mediation and compromise common (Steiner et al., 2004)? What are the common themes and rationales for the groups' policy recommendations (DeVries et al., 2013)? Are facts used accurately—and if not, do the participants correct each other? Are the participants keeping to the task? Is there evidence of polarization? Do the comments reflect appeals to a 'common good' perspective or are the reasons given for opinions mostly based on partisan perspectives?

### **Limiting the Potential Pitfalls of DD Methods**

The potential pitfalls of the deliberative process are widely discussed among scholars of deliberation, with the main concerns having to do with group dynamic factors (Mendelberg et al., 2002; Carpinì et al., 2004; Levine et al., 2005; Ryfe, 2005). A key worry about DD methods is that rather than arriving at a 'common good' based policy recommendation, DD will lead to group polarisation (Sunstein, 2002 & 2007). In group polarisation, deliberators move to more extreme positions in the direction of their own pre-deliberation opinions (Sunstein, 2002). This may occur because participants gather selective information supportive of the views they already hold from peers who are like-minded. Thus their prior opinions are not challenged and indeed grow more extreme. Polarisation may occur also because of social comparison/peer pressure (the simple desire to be perceived favorably by the group), and confidence by corroboration (people gain confidence after feeling group support, so more extreme viewpoints can be expressed) (Sunstein, 2007).

Steps can be taken to minimize polarization. Rather than a gathering based on affinity, DD participants should be randomly chosen. DD procedures that are careful to introduce balanced information may be less susceptible (Sunstein, 2002). To counteract the reduced argument pool in groups that already favor one view over another, balanced expert information is crucial, and careful vetting by various perspectives is important. Group facilitation by an independent facilitator is crucial in helping to curb the natural group polarising tendencies by ensuring that participation is equitable and respectful of minority views, and by encouraging arguments based on giving of reasons and rationales rather than simply asserting strongly held positions.

It is crucial to note that no method of opinion elicitation is perfect and every method has its own potential pitfalls. The question is a comparative one. It is not a question of whether DD methods are perfect but instead whether, when compared to traditional survey methods, their additional cost, effort, and potential pitfalls are outweighed by its ability to elicit considered and educated opinions of the participants.

## **Conclusion**

There are many potential bioethics topics that could be addressed using DD-based methods. Some of these topics have already been well-described in the literature (Gutmann and Thompson, 1997). In general, any bioethics topic with broad policy implications that require a genuine tradeoff of goods or values (e.g. individual privacy and control versus welfare of community) would be a potential candidate. However, because DD studies are challenging and expensive, researchers should continue to address methodological issues in their DD studies. In particular, future refinements should focus on maximising validity while at the same time minimising cost. For example, given the challenges to external validity posed by recruiting people to an all-day (or even several day) event, if broadly generalisable data are needed for a particular policy issue, then it may make sense to conduct a DD study in combination with a relatively less expensive but more representative (e.g., national probabilistic sample) cross-sectional traditional survey.

Democratic deliberation and bioethics are natural allies. They both take the normative opinions of the lay public seriously, and strive to elicit and be guided by those opinions. Such opinions are especially valuable when normative analysis alone cannot provide sufficient policy guidance and when a perspective beyond special interest politics is sought. Of course, no method of eliciting such opinions is without limitations and potential pitfalls. However, DD methods are more likely than traditional methods to elicit the considered moral judgment of ordinary citizens regarding challenging and controversial bioethics policy issues.

## **References**

- Abelson, J., E. Blacksher, K. Li, S. Boesveld and S. Goold (2013). "Public Deliberation in Health Policy and Bioethics: Mapping an emerging, interdisciplinary field." *Journal of Public Deliberation* **9**(1).
- Arlidge, E. (2004). *The Forgetting: A Portrait of Alzheimer's*. USA, PBS Paramount.
- Bohman, J. and W. Rehg (1997). *Deliberative Democracy: Essays on Reason and Politics*. Cambridge, MA, The MIT Press.
- Botkin, J. R., E. Rothwell, R. Anderson, L. Stark, A. Goldenberg, M. Lewis, M. Burbank and B. Wong (2012). "Public Attitudes Regarding the Use of Residual Newborn Screening Specimens for Research." *Pediatrics* **129**(2): 231-238.
- Bravo, G., M. F. dubois, S. M. Wildeman, J. Graham, C. A. Cohen, K. Painter and S. Bellemare (2010). "Research with decisionally incapacitated older adults: practices of Canadian research ethics boards." *IRB: Ethics & Human Research* **32**(6): 1-8.



Bravo, G., M. Paquet and M. F. Dubois (2003). "Opinions regarding who should consent to research on behalf of an older adult suffering from dementia." *The International Journal of Social Research and Practice* **2**: 49-65.

Cahill, M. and A. Wichman (2000). "Research Involving Persons with Cognitive Impairments: Results of a Survey of Alzheimer Disease Research Centers in the United States." *Alzheimer Disease and Associated Disorders* **14**(1): 20-27.

Carman KL, M. M., Mallery C, Wang G, Garfinkel S, Richmond J, Gilmore D, Windham A, Yang M, Mangrum R, Ginsburg M, Sofaer S, Fernandez J, Gold M, Pathak-Sen E, Davies T, Siu A, Fishkin J, Rosenberg M, Fratto A. (2013). *Community Forum Deliberative Methods Demonstration: Evaluating Effectiveness and Eliciting Public Views on Use of Evidence: Executive Summary*. AHRQ. Rockville, MD, Agency for Healthcare Research and Quality.

Carpini, M. X. D., F. L. Cook and L. R. Jacobs (2004). "Public Deliberation, Discursive Participation, and Citizen Engagement: A Review of the Empirical Literature." *Annual Review of Political Science* **7**(1): 315-344.

Carson, L., J. Hartz-Carp, J. Gastil and P. Levine (2005). *Adapting and combining deliberative designs*. *The Deliberative Democracy Handbook*. San Francisco, Jossey-Bass: 20-36.

Chambers, S. (2003). "Deliberative Democratic Theory." *Annual Review of Political Science* **6**(1): 307-326.

Cohen, J. (2007). *Deliberative democracy. Deliberation, Participation and Democracy: Can the People Govern?* S. Rosenberg. Basingstoke, UK, Palgrave Macmillan: 219-236.

Crosby, N., D. Nethercut, J. Gastil and P. Levine (2005). *Citizens juries: creating a trustworthy voice of the people*. *The Deliberative Democracy Handbook*. San Francisco, Josey-Bass: 111-119.

Damschroder, L. J., J. L. Pritts, M. A. Neblo, R. J. Kalarickal, J. W. Creswell and R. A. Hayward (2007). "Patients, Privacy & Trust: Patients' Willingness to Allow Researchers to Access their Medical Records." *Social Science & Medicine* **64**(1): 223-235.

De Vries, R., A. Stanczyk, K. Ryan and S. Y. H. Kim (2011). "A Framework for Assessing the Quality of Democratic Deliberation: Enhancing Deliberation as a Tool for Bioethics." *Journal of Empirical Research on Human Research Ethics* **6**(3): 3-17.

De Vries, R., A. Stanczyk, I. F. Wall, R. Uhlmann, L. J. Damschroder and S. Y. Kim (2010). "Assessing the quality of democratic deliberation: A case study of public deliberation on the ethics of surrogate consent for research." *Social Science & Medicine* **70**(12): 1896-1903.

DeVries, R. G., K. A. Ryan, A. Stanczyk, P. S. Appelbaum, L. Damschroder, D. Knopman and S. Kim (2013). "Public's Approach to Surrogate Consent for Dementia Research: Cautious Pragmatism." *Am J Geriatr Psychiatry* **21**: 364-372.

Elster, J. (1998). *Deliberative Democracy*. New York Cambridge University Press.

Fishkin, J. S. (1997). *The Voice of the People*. New Haven, CT, Yale University Press.

Fishkin, J. S. (2006). "Beyond polling alone: The quest for an informed public." *Critical Review* **18**(1-3): 157-165.

Fishkin, J. S. and R. C. Luskin (2005). "Experimenting with a Democratic Ideal: Deliberative Polling and Public Opinion." *Acta Politica* **40**(3): 284-298.

Freeman, S. (2000). "Deliberative democracy: a sympathetic comment." *Philosophy & Public Affairs* **29** (4): 371-419.

Gastil, J. and W. M. Keith (2005). *A nation that (sometimes) likes to talk: a brief history of public deliberation in the United States*. *The Deliberative Democracy Handbook*. J. Gastil and P. Levine. San Francisco, Jossey-Bass: 3-17.

- Gastil, J. and T. Kelshaw (2000). Public meetings: A sampler of deliberative forums that bring officeholders and citizens together. Dayton, OH, Kettering Foundation.
- Gong, M. N., G. Winkel, R. Rhodes, L. D. Richardson and J. H. Silverstein (2010). "Surrogate consent for research involving adults with impaired decision making: survey of Institutional Review Board practices." *Crit Care Med* **38**(11): 2146-2154.
- Goold, S. D., M. A. Neblo, S. Y. H. Kim, R. De Vries and P. Muhlberger (2012). "What is good quality public deliberation?" *Hasting Center Report* **42**(2): 24-26.
- Gregory, J., J. Hartz-Karp and R. Watson (2008). "Using deliberative techniques to engage the community in policy development." *Australia and New Zealand Health Policy* **5**(1): 16.
- Gutmann, A. (2011). "The ethics of synthetic biology: guiding principles for emerging technologies." *Hastings Cent Rep* **41**(4): 17-22.
- Gutmann, A. and D. Thompson (1997). "Deliberating about bioethics." *Hastings Center Report* **27**(3): 38-41.
- Haidt, J. (2012). *The righteous mind : why good people are divided by politics and religion*. New York, Pantheon Books.
- Hoffmann, D. E. and J. Schwartz (1998). "Proxy consent to participation of the decisionally impaired in medical research--Maryland's policy initiative." *J of Health Care Law and Policy* **1**(1): 123-153.
- Institute of Medicine (2011). *Essential Health Benefits: Balancing Coverage and Cost*. Washington DC, Intitute of Medicine of the National Academies.
- Jonsen, A. R. (1998). *The birth of bioethics*. New York, Oxford University Press.
- Karlawish, J., J. Rubright, D. Casarett, M. Cary, T. Ten Have and P. Sankar (2009). "Older adults' attitudes toward enrollment of non-competent subjects participating in Alzheimer's research." *Am J Psychiatry* **166**(2): 182-188.
- Karlawish, J. H. T., D. Knopman, C. M. Clark, J. C. Morris, D. Marson, P. J. Whitehouse and C. Kawas (2002). "Informed consent for Alzheimer's Disease clinical trials: a survey of clinical investigators " *IRB: Ethics and Human Research* **24**(5): 1-5.
- Kim, S. Y. H. (2011). "The ethics of informed consent in Alzheimer disease research." *Nat Rev Neurol* **7**: 410-414.
- Kim, S. Y. H., E. D. Caine, G. W. Currier, A. Leibovici and J. M. Ryan (2001). "Assessing the competence of persons with Alzheimer's disease in providing informed consent for participation in research." *American Journal of Psychiatry* **158**: 712-717.
- Kim, S. Y. H., H. M. Kim, D. S. Knopman, R. De Vries, L. Damschroder and P. S. Appelbaum (2011). "Effect of public deliberation on attitudes toward surrogate consent for dementia research." *Neurology* **77**(24): 2097-2104.
- Kim, S. Y. H., H. M. Kim, K. M. Langa, J. H. T. Karlawish, D. S. Knopman and P. S. Appelbaum (2009). "Surrogate Consent for Dementia Research: A National Survey of Older Americans." *Neurology* **72**: 149-155.
- Kim, S. Y. H., H. M. Kim, C. McCallum and P. N. Tariot (2005). "What do people at risk for Alzheimer's disease think about surrogate consent for research?" *Neurology* **65**: 1395-1401.
- Kim, S. Y. H., H. M. Kim, K. A. Ryan, P. S. Appelbaum, D. S. Knopman, L. Damschroder and R. De Vries (2013). "How Important Is "Accuracy" of Surrogate Decision-Making for Research Participation?" *PLoS ONE* **8**(1): e54790.

- Kim, S. Y. H., R. A. Uhlmann, P. S. Appelbaum, D. S. Knopman, H. M. Kim, L. Damschroder, E. Beattie, L. Struble and R. De Vries (2010). "Deliberative assessment of surrogate consent in dementia research." *Alzheimer's and Dementia* **6**(4): 342-350.
- Levine, P., A. Fung and J. Gastil (2005). "Future directions for public deliberation." *Journal of Public Deliberation* **1** (1): Article 3, 1-13.
- Levine, R. J. (1986). *Ethics and regulation of clinical research*. New Haven, Yale University Press.
- Lukensmeyer, C. J., J. Goldman, S. Brigham, J. Gastil and P. Levine (2005). A town meeting for the twenty-first century. *The Deliberative Democracy Handbook*. San Francisco, Josey-Bass: 154-163.
- Melville, K., T. L. Willingham, J. R. Dedrick, J. Gastil and P. Levine (2005). National Issues Forums: A Network of Communities Promoting Public Deliberation. *The Deliberative Democracy Handbook*. San Francisco, Josey-Bass: 35-58.
- Mendelberg, T., M. X. Delli Carpini, L. Huddy and R. Shapiro (2002). *The deliberative citizen: theory and evidence. Research in micropolitics: political decisionmaking, deliberation, and participation*. Greenwich, CT, JAI Press: 151-193.
- Mitton, C., N. Smith, S. Peacock, B. Evoy and J. Abelson (2009). "Public participation in health care priority setting: A scoping review." *Health Policy*.
- Neblo, M. A. (2007). Change for the Better? Linking the mechanisms of deliberative opinion change to normative theory. *Annu. Meet. Int. Soc. Polit. Psychol.* Toronto.
- Nuffield Council on Bioethics (2008). *Dementia: Ethical Issues (Consultation Paper)*.
- Okonkwo, O., H. R. Griffith, K. Belue, S. Lanza, E. Y. Zamrini, L. E. Harrell, J. C. Brockington, D. Clark, R. Raman and D. C. Marson (2007). "Medical decision-making capacity in patients with mild cognitive impairment." *Neurology* **69**(15): 1528-1535.
- Ryfe, D. M. (2005). "Does deliberative democracy work?" *Annual Review of Political Science* **8**(1): 49-71.
- Saks, E. R., L. B. Dunn, J. Wimer, M. Gonzales and S. Y. H. Kim (2008). "Proxy Consent to Research: The Legal Landscape." *Yale Journal of Health Law, Policy, and Ethics* **8** (1): 37-78.
- Secko, D. M., N. Preto, S. Niemeyer and M. M. Burgess (2009). "Informed consent in biobank research: A deliberative approach to the debate." *Social Science & Medicine* **68**(4): 781-789.
- Steiner, J., A. Bachtiger, M. Spornli and M. Steenbergen (2004). *Deliberative Politics in Action: Cross-national Study of Parliamentary Debates*. Cambridge, UK, Cambridge University Press.
- Sunstein, C. R. (2002). "The Law of Group Polarization." *Journal of Political Philosophy* **10**: 175-195.
- Sunstein, C. R. (2007). "Group Polarization and *12 Angry Men*." *Negotiation Journal* **23**(4): 443-447.
- Thompson, D. F. (2008). "Deliberative Democratic Theory and Empirical Political Science." *Annual Review of Political Science* **11**(1): 497-520.
- Wendler, D., R. A. Martinez, D. Fairclough, T. Sunderland and E. Emanuel (2002). "Views of Potential Subjects Toward Proposed Regulations for Clinical Research With Adults Unable to Consent." *American Journal of Psychiatry* **159**(4): 585-591.

# Feminist empirical bioethics

Jackie Leach-Scully

This chapter examines the feminist contribution to empirical ways of doing ethics, and especially of doing bioethics. The focus on bioethics reflects the high level of feminist empirical activity in that field of ethical inquiry. This is not to suggest that there is no feminist work going on in other forms of ethics than bioethics: distinctively feminist perspectives are present and have influence throughout contemporary moral philosophy, in social and political theory, and other areas of applied ethics. But in practice, bioethics has been notably and distinctively open to empirical forms of inquiry, exemplified in its taking of the so-called empirical turn (Borry et al, 2005) over the last 20 years.

One reason for this openness is the substance of the issues that bioethics addresses. Most often, these are to do with advances in biomedical knowledge that lead to new forms of theoretical understanding in the life sciences, or of practical healthcare, or both. They tend to present new moral dilemmas because they involve acts, relationships and identities that may be completely new, or transformed versions of more familiar ones. Think, for example, of how the introduction of assisted reproductive technologies has generated not just new babies but also new ways of thinking about babies, new ways of being parents, and also new ways of linking public healthcare policy to private family life. In these situations, the need to base normative ethical judgements on *what is actually going on*, rather than just extrapolating from *how things have been or appear to be*, is clear. And on the new social territory formed through interaction with technological change, getting an adequate understanding of what the feminist philosopher Margaret Urban Walker called “actual moral and social orders” (Walker, 2008:195) means undertaking empirical research. New technologies and the resulting social practices, then, do not just create new empirical realities, but can also open up conceptual space for fresh, empirically based ethical thinking. Bioethics is rarely ‘ethics as usual’ (and if it is, it probably isn’t good bioethics).

So although much of what I say about feminist empirical approaches is applicable to ethics overall, specific examples will relate to recent work that has flourished within feminist bioethics. I’ll also have something to say about the distinctive features of an academic discipline (i.e. feminist ethics) that emerged out of an activist movement with avowedly ideological aims (i.e. feminism), and what that implies for the ethics of the discipline itself. Throughout I understand ‘empirical’ in the broadest sense, to include any ethical inquiry that draws in a meaningful way on real world material. This may be a looser definition than many social scientists would be comfortable with, but I use it to mark as clear a distinction as possible between this way of doing ethical work, and approaches that depend more or less entirely on abstract arguments that seem compelling to the individual ethicist. I therefore include ethics that undertakes original research using standard social science methodologies, both quantitative and qualitative ones such as interviews, questionnaires, and ethnographies; but I also include forms of ethical and especially bioethical reflection that consciously and conscientiously draw on empirical data about real world practices, acquired by others, to provide a factual basis for theoretical assertion and the crafting of good and workable policy.

## The bioethical turn to the empirical

The empirical turn in bioethics is usually explained as being driven, at least in part, by the unsympathetic critique coming from the social sciences (see, for example, Zussman, 2000; Holm & Jones 2004; DeVries et al, 2007; Turner, 2009; Hoeyer, 2006). It is important to note that the social science critique is not directed solely to the lack of a sound empirical basis for many of the claims that bioethicists make. More generally, it takes in the epistemic resources, conceptions of moral agency and subjectivity, and forms of rationality particularly favoured by moral philosophy and, by extension, first-wave philosophical bioethics. Beyond the accumulation of more facts from the frontlines of medicine and healthcare, curing bioethics’ “abstraction from sociopolitical realities of everyday life”

(Twine, 2010:53) requires a fundamentally different approach to bioethical thinking. What has been called (at least by those who advocate it) *critical bioethics* (Hedgecoe, 2004; Twine, 2005), which emerged as the empirical turn was gaining momentum, also makes the case that bioethicists need to do more than “root their enquiries in empirical research”; they also have to “challenge theories, using evidence, to be reflexive and to be skeptical about the claims of other bioethicists, scientists and clinicians” (Hedgecoe, 2004:120). This is an empirical approach that aims to go beyond the straightforward documentation of ethical situations and decisions, providing a methodology for analysing them and ultimately making (better) normative judgements about them.

These demands for more empirically grounded and critically minded bioethical approaches routinely overlook the pioneering and on-going contribution of feminist ethics and bioethics to that work (Tong 1997; Scully et al, 2010). The claim that good normative ethical judgements can't be made without empirically based knowledge of what really goes on in the world has been a key feature of decades of feminist social and political ethics. Equally, it is feminist theory's longstanding epistemological and ethical commitments that have driven its skeptical examination of the social, economic and political arrangements that determine precisely which empirical questions are asked, and who gets to ask them.

### **Feminist ethics and bioethics**

*“The question of what constitutes a specifically feminist bioethics is far from self-evident, and it is certain that no one definition could tie up all the avenues of approach that one could claim to be feminist.”* (Shildrick, 2008: 29)

At the heart of feminist ethics and bioethics lies the basic observation that dominant ways of doing ethics and bioethics are gendered. This means more than that most professional ethicists are male (although that is usually the case): it is a claim about the nature of the societies within which ethical thinking is carried out and the way that practices and institutions of bioethics are organised. It implies that the perspective from which bioethics detects morally troubling issues in the health or life sciences, and their ethically salient features, is likely to be skewed in ways that track along gendered lines. A further implication is that such bias is likely to “contribute to culturally inscribed oppressive practices” (Fitzpatrick & Scully, 2010:3).

What *feminist empirical ethics* offers, then, is a tradition and a toolkit for critical engagement with the politics of ethical and bioethical life. Feminist ethics starts from the premise that many of the empirically discernible facts on the ground are not in any meaningful sense ‘natural’ (Jaggar, 1991; Tong, 2013). They don't just happen, but are the result of social organisations that mean certain features and values of social life are taken for granted and that some outcomes are more likely than others. Feminist inquiry therefore looks long and hard at the socially and politically derived power relations inherent in ways of knowing within philosophical thought.

But it is also more overtly political. Feminism has the ultimate goal of achieving equality and justice for women (and other marginalised groups too), and this has some fairly significant consequences for any feminist-inspired approach to ethics (Jaggar, 1991). For one thing, it can't risk being relativist – at least not as ethical relativism is generally understood.<sup>67</sup> To diagnose certain ways of providing healthcare or of using life science knowledge as contributing to gender oppressive practices means that there are alternatives that do not, and that therefore ought to be preferred. As a discipline, then, feminist bioethics is constantly striving to reflect both its allegiance to the values of properly rigorous academic inquiry and its commitment to the strategic goal of gender justice and equality. Balancing the two is not always an easy task.

### **Feminist ontology and epistemology**

<sup>67</sup> See Sheehan's (2016) chapter, in this volume, for a detailed discussion of moral relativism and how can be understood.

Feminist ethics' political commitment is one reason for its bias towards empirical methodologies of the kind discussed in this book. Clearly, not all forms of feminist ethics are empirical, and many feminist theoretical ethicists would be justifiably irritated at the suggestion. Nevertheless, the aim of uncovering the structures that generate those actual (and actually oppressive) moral and social orders mentioned earlier is often best served by a rigorous empirical inquiry into what happens in real life. Equally important to feminist ethics' empirical basis, however, are feminist theory's characteristic ontology and epistemology. These distinctive features have driven a fundamental reconsideration of moral philosophy's central concepts of the moral self, agency, and autonomy, and of its favoured modes of information gathering and reasoning.

Feminists argue that the models of the self and of the moral agent that philosophical bioethics has tended to adopt are profoundly shaped by the gendered political and intellectual environments within which they were first devised (Stanley & Wise, 1993; Mackenzie & Stoljar, 2000). In traditional moral and political philosophy the moral self is characterised as an atomised, disembodied, socially disembedded, effectively interchangeable locus of consciousness, whose moral deliberations are aimed at maximising the benefits to themselves through rationally arrived at and usually reciprocal arrangements with others. Critics of this model of the moral self, not all of them feminist, reject it on the grounds that it leaves out fundamental features that are essential to real moral selfhood and agency. Moral subjects, the argument goes, are also embodied and emotional beings who are connected to each other in wider interpersonal and social networks of dependency, responsibility and necessity that are often neither reciprocal nor rationally deliberated (Lindemann-Nelson, 2000).<sup>68</sup>

The traditional ontological norm tends to be accompanied by a particular epistemological view as well. Classical moral philosophy works with an epistemic norm of a single subject in conscious search of the knowledge that she needs in order to make her reasoned and (bio)ethically sound decisions. This kind of epistemic subject is primarily concerned with assembling information from relevant sources, determining its accuracy and authority, and avoiding biases either in her acquisition of information or her interpretation of it, before then using that information to support rationally defensible processes of ethical evaluation. It's worth noting that, according to this picture of the moral subject and the processes of ethical evaluation she undertakes, empirical approaches *in themselves* do not present any notable challenge to the epistemological framework of mainstream philosophical bioethics.

However, one consequence of the feminist theoretical view of subjectivity and agency as generated through social roles and relationships, is that the resources available to, and processes involved in, the moral subject's normative deliberation have to be reconsidered. A socially constituted self has epistemic and imaginative resources that may well differ significantly from those of the isolated self of traditional moral philosophy. Her view of what counts as impartiality or objectivity in moral deliberation may be different as well.

Feminist ontology therefore raises questions both about the *kind* of knowledge needed to back up normative judgements, especially judgements about the practices and values of people with experiences very different from our own, and the *nature* of the normative judgements that can be made. The philosophical tradition that understands ethics ideally as "abstract, general in form, and independent of unique circumstances, social contexts, or cultural backgrounds" (Rehmann, 2010:38) necessarily also dismisses not just women's perspectives, but the notion of (epistemological and moral) perspectives altogether. Feminist ethics, by contrast, argues that all ethical evaluations are based on experience and discourse, that all experience occurs within historically and culturally defined contexts, and all discourse is situated within some personal perspective or other. Neither the experiences that bioethics is interested in, nor the discourse of bioethics itself, are any exception.

Characteristically, feminist epistemologies are social ones that shift the focus of attention away from the individual acquiring and processing information, and onto the social structures within which knowledge is formed, exchanged, given value or rejected. Feminist epistemologies specifically charge that gendered arrangements of social advantage and disadvantage lead to equally gendered

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<sup>68</sup> Proponents of a more traditional ontology may respond, with some justification, that the critique targets an out-dated caricature, and that rather more nuanced views of moral subjectivity are held in contemporary moral philosophy. I would argue, however, that much of bioethics, where it discusses the nature of the moral self at all, still rely heavily on this unreconstructed view of the detached and disembodied moral subject.

distributions of epistemic authority. Feminists and other theorists from marginal perspectives are mostly concerned with the epistemic effects of social positioning: the difference that belonging to a particular social category makes to the knowledge that one has, and also to the credibility that such knowledge has in the eyes of differently situated others. The claim is that being a member of a particular social category influences people's experiences, and as a result certain sensitivities are promoted and certain values or outcomes prioritised.

Standpoint epistemologies go on to make the further claim that social asymmetries are reflected in epistemic asymmetries as well. Differences in how events are perceived and interpreted follow not from the observer's social identity *per se* - it isn't that because you are a woman you will necessarily display certain cognitive and affective characteristics - but because the social norms and behaviours that go along with that identity open up particular perspectives that are not associated with other identities (Harding, 1991; Hartsock, 1987 & 1995; Wylie, 2003). Members of any marginalised social group, for example, are likely to gain particularly acute insight into the domains of life that are most affected by the holding of subordinate social positions. Feminists are primarily, but not exclusively, interested in the epistemic and ethical effects of the social positioning that comes about as a result of being a woman. Feminist standpoint epistemology, therefore, does not claim that the insights of women are necessarily better, but only that those most affected by gendered injustice are also the ones most likely to be able to spot where and how it occurs.

A pioneering and formative feminist text that developed a robust case for a critical social epistemology was Margaret Urban Walker's *Moral Understandings* (1998). In it, Walker argues that any kind of ethical work is carried out within a framing history of important, but generally unacknowledged, prior decisions about such things as: what constitutes a moral problem in the first place; what credible ethical evaluation looks like; and who has the authority to make (and impose) normative judgements. Walker describes conventional moral philosophical analysis as operating with what she calls a theoretical-judicial template. It sees moral theory as "a compact, propositionally codifiable, impersonally action-guiding code" or "a compact set of law-like propositions that 'explain' the moral behaviour of a well-formed moral agent" (Walker, 1998:7-8). Her counterargument is that this template bears little relation to the activities of real moral life, where ethics is a collaborative social practice through which relationships, responsibilities and commitments are agreed upon and consolidated. She argues that the attention of ethicists should be shifted away from the making of ethical end-judgements and decisions, which form a very minor part of moral life, and redirected towards the epistemically and ethically prior world of moral perceptions, descriptions, narratives, defences, explanations and so on.

Crucially, these features of moral life are also amenable to empirical examination. Indeed, Walker contends that genuine ethical analysis is impossible without a deep understanding of the ways in which moral theories and normative judgements are made meaningful through practices and discourses. If ideas about moral good and moral selves are generated out of the concrete circumstances of relationship and communities, then evaluating these goods and selves normatively requires a grasp of the specific ways in which they are understood in those contexts, and – for bioethics in particular -- how such understandings may be changed, for example through the adoption of a new biomedical technology. This is of course an empirical project, and Walker and other influential feminist philosophers such as Annette Baier (1995) see generating such an 'empirically saturated' analysis as a central, and neglected, task of all ethics.

Redirecting ethicists' attention towards the social, cultural and political contexts of knowledge also entails a more critical stance towards the kind of (moral) knowledge that is going to be taken as authoritative. The feminist critique of standard empirical approaches to ethics is that they take for granted that we (the inquirers) are already familiar enough with the agents, acts and attitudes involved that we can assess them ethically. It is a form of epistemological myopia, or possibly arrogance, that assumes that people don't vary much in terms of how they identify a situation of moral difficulty, frame the problem, identify and weigh up the salient features, and so on. Being conscious that this assumption might be flawed is particularly crucial in the case of bioethics' engagement with radically new social practices and identities that are often generated by innovations in the health and life sciences. Before attempting normative judgement of egg donation, for example, it is necessary to

know how egg donation *actually happens*: how it is formally regulated and institutionally organised, but also how women go about donating and receiving eggs, how they make the relevant decisions, who they talk to about them, where they get information, what can go wrong, what sorts of language, opinions and practices shape the emerging social identity of the egg donor (and especially of the 'good' egg donor who has donated eggs in what those involved consider to be an ethically responsible way), and so on.

Moreover, if there is empirical evidence that an act or identity is vulnerable to systematic misrepresentation, there are additional implications for doing bioethics responsibly. Many feminist bioethicists would argue that part of their task is to critically examine and help to improve the representations, narratives and cultural practices that provide the epistemic resources serving normative thinking by both professional ethicists and the general public. The epistemic humility inherent in standpoint epistemology offers some protection against the trap of assuming that even empirical data on bioethically relevant practices will necessarily enable ethical observers (that is, us) to occupy the same epistemic or moral space as any of the agents directly involved in or affected by those practices.

It is precisely because of these theoretical commitments, then, that feminist ethics has an empirical orientation. That is not to say that all feminist approaches to ethics therefore have to be empirical. But the theoretical arguments that experience is gendered, that relationships are most commonly asymmetric in terms of power and dependence, or that a person's social and cultural positioning generally results in epistemic and analytical bias, all point towards the need for what some feminist bioethicists have called a 'naturalised bioethics' (Lindemann et al, 2008), better grounded in the natural, social, political and institutional worlds. This is a bioethics with a sense of the empirical realities of practices under ethical scrutiny: both a fine grained understanding of what actually goes on rather than what we think goes on, and a broader, more skeptical perspective on the reasons why particular practices – and especially ethically troubling practices – take place.

Its ontological and epistemological commitments mean that a central part of feminist ethics' project is also to re-examine what counts as ethically valid and relevant information, how ethical issues are described, whose experiences count as data, and how an issue is defined as 'ethical' at all. This re-examination of ethical orthodoxies predates, but converges with, the more recent calls for a 'critical bioethics'. From its outset, feminist theory has provided ethics with tools for examining the relationship between social position and the generation of knowledge: how the social organization of authority determines what it is possible for people to know and to think. Critical approaches to ethics acknowledge that even the idea of what counts as 'valid' ethical evaluation is a consensus produced within practices, discourses and institutions that are themselves shaped by social and political dynamics. According to Walker, such relations of dominance and authority "allow some people....to obscure what is really happening to whom and why." This idea underpins feminist ethics' distinctive understanding of empirical ethical inquiry, as aiming to provide a "fund of knowledge that needs to be enlarged and theoretically articulated in general accounts and specific studies of different relative moral positions in differentiated social lives" (Walker 1998:219).

### **Distinctive features rather than distinctive methodologies**

In the preceding discussion of the theoretical basis for, and distinctive features of, feminist empirical ethics, I have tried to avoid suggesting that there are defined methodologies that feminist bioethics adopts, or ought to adopt, to do its empirical work. What is distinctive about *feminist* inquiry into an ethical issue has more to do with the features that it prioritises for empirical examination: the elements of the story to which it pays particularly close attention.

#### *Paying attention to power structures*

With its origins in a project that was catalysed by, and has gone on to examine in great depth, the experience of being 'other' to the gender norm and how the position of the 'other' is generated and



stabilised, contemporary feminist bioethics requires “that we look at society ... and at the dominance of some voices and the exclusion of others within societal and professional conversations about morality and ethics” (Walker, 2010:3). As a result feminist ethics has an acute sensitivity to the asymmetric power relationships threading through social, political and economic structures that differentially disadvantage women (and a whole range of other marginalities too).

Feminist ethics’ argument is that mainstream philosophical ethics’ habits of abstraction, decontextualisation, and the drive to universality are not of themselves wrong, but that they at best obscure, and at worst exacerbate, the biases of the human collectives within which these ethical analyses are made. Thus a central difference between feminist and most other empirical approaches in bioethics is that the former holds a commitment to go beyond providing an empirically enriched knowledge of situation and context, and to dissect out the biases inherent in the “concepts, ideals, and methods of the Western ethical tradition” (Jaggar, 2000:462) that inevitably reflect the epistemic, and other, structures of the societies in which that tradition was developed.

As a result, feminist bioethics entails a politically astute scrutiny of the relationships of power and authority present within many of the situations it has to address. These include differences in professional standing, social status, knowledge, dependency, and vulnerability. Such differences shape the interaction between providers of healthcare and knowledge (of different sorts) and the recipients of that care or knowledge. Traditionally, clinical and research ethics have been very good at attending to the imbalances of power and authority between individual physicians or other healthcare professionals and their patients (and sometimes their families) in the context of the clinic or research. Bioethics is practiced at elaborating principles and guidelines that provide some protection against abuses or exploitation within these mostly dyadic relationships. But until quite recently, mainstream bioethics has been markedly less conscious than feminist ethics of the larger scale distributions of power that result from social stratifications including class, ethnicity, sexuality, disability, and so on, and which – feminist critics would argue -- are also essential to a comprehensive ethical understanding. For example, explorations of the ethics of stem cell research have tended to focus on the moral status of the embryo, sometimes set against the moral claims of those who might be helped by stem cell-based therapies (see e.g. Holland et al, 2001; Brown, 2013). By contrast, feminist analyses are more likely to focus on power disparities of different kinds: between stem cell researchers and the women donating embryos for research, but also the larger-scale social and political forces that make women more vulnerable to ethically problematic practices, such as a global trades in oocytes or embryos (Baylis & McLeod 2007; Dickenson, 2006).

Much classic feminist bioethical work has been concerned with the gendered experience of healthcare or biomedical research. ‘Gendered experience’ here covers both the fact that women encounter different events from men (menstruation and pregnancy being obvious examples), and that they experience common events differently from men (such as differential access to clinical trial participation). However, at least as much attention has been given to the ways in which women’s particular accounts of their experience are excluded from, or included within, bioethical discourse. If, as many feminist ethicists would argue, moral understandings are generated as communities and societies deliberate over evidence and interpretation, it is necessary to ask those communities and societies questions about who is given (or takes) authority to be part of these deliberations, and whether the resulting allocations of epistemic and ethical authority are just or not. And while this skeptical perspective was first applied to gendered power arrangements, it equally well gives feminist bioethics the capacity (and, some would say, the responsibility) to apply the same sort of excavatory gaze to other stigmatised social categories, and the ways in which the experiences and accounts of their members are handled.

### *Paying attention to relationality and care*

Feminist ethics is further characterised by its attention to the fact that human beings live in connection with each other. Although feminist bioethics has often focused on (and been condemned by its critics for focusing on) close interpersonal relationships between family members, or between healthcare workers and patients, or researchers and research participants, it is also concerned with the larger

scale relationships constructed through social organisations and formal institutions (Gilligan, 1982; Tronto, 1993; Carse & Lindemann-Nelson, 1996).

This attentiveness to relationality has often led to the conflation of feminist ethics and the ethics of care. Not all feminist ethicists are concerned with issues of care, however, and not all care ethics is feminist. Nevertheless, there are several reasons why feminist bioethics has taken a particular interest in questions of care as they arise within health and life sciences. One is the gendered nature of the practices of care (Kittay, 1999; Kittay & Feder, 2002; Eckenwiler, 2013). Care ethics makes the normative claim that moral deliberation can or should be, and empirically often is, based on caring for and about others. In this context care can be the hands-on labour of some people looking after others who are physically dependent, such as children or frail elderly people, but it can also be understood as a central moral value, and as an ethical orientation towards others. What is key to all conceptualisations of care is the foregrounding of connections between individuals and within communities, and of the vulnerabilities that they generate. Care ethics emphasises both dependencies and interdependencies as central to moral response. Moreover, care ethics also recognizes that human relationships are very often asymmetric rather than reciprocal.

At least some forms of care ethics have been accused of essentialising the link between women and care practices: implying that the fact that women undertake the bulk of care labour says something about women's intrinsic caring nature rather than about more complex social and economic organisations. The charge is that in doing so care ethics reinforces highly conservative views about gender roles. Nevertheless, it is an empirically verifiable observation that globally, most caregivers are women, whether they do unpaid care work within the family or are employed to give care to others who need it. A substantial amount of pioneering empirical feminist work has been devoted to examining the ethical consequences, for women and men, of care practices around the world.

Lisa Eckenwiler's (2013) recent work on global care relations is an example of feminist bioethics addressing an issue that can be shown empirically to affect women more than men. It also illustrates how existing empirical data can be used in a forensic examination of global economic and political inequalities that are gendered in complex, and sometimes unexpected ways. Eckenwiler draws on a wide range of academic research, policy documents, grey literature and other resources to inform a discussion of the processes through which the economy of long-term care is being transformed by radically shifting age profiles in most countries of the world. Eckenwiler is of course not the first to point out the consequences of an ageing and increasingly disabled population. Other writers in public health have described a burgeoning cadre of long-term care workers who, because of the low status given to care (which is itself a function of the gendered nature of such work) and chronic underinvestment in the care sector, find themselves working and living in extremely poorly resourced conditions (Eckenwiler, 2013). Feminist ethicists have also examined the role of family caregivers who, often with little or no social support, "strive to support their loved ones and often suffer ill health themselves" (Eckenwiler, 2013) as a result (Lanoix, 2013; Tong, 2013b). Eckenwiler's work, however, extends a global empirical reach to consider the implications, both for the carers and those in need of care, of encouraging the migration of healthcare workers from the 'source countries' of Africa, the Philippines, India, China and South Korea, even though many of these places have their own rapidly growing long-term care needs: "The state of long-term care policy in the United States [and other developed countries] is contributing, however indirectly and unintentionally, to global workforce shortages and deepening health inequalities" (Eckenwiler 2013:2). This work is most obviously feminist because it focuses on an aspect of healthcare that is heavily gender-specific, and where despite the importance of the work that they do the women involved tend to remain invisible because they slip under the gendered radar of most bioethics. Eckenwiler cites numerous empirically based sources to substantiate her claims that "[a]dult daughters provide the most care" and that family caregiving "represents a critical piece of the global health workforce that is poorly documented and understood" (2013:21). The inclusion of unpaid care labour in this account is classically feminist; theorists of the gendered social relations of production note that although unpaid care work makes an essential contribution to the processes of production, it is discounted by standard economic theories which ignore what is produced in the home as opposed to products that can be exchanged on the market. Finally, Eckenwiler's work is also distinctively feminist in that it is consciously attuned to power asymmetries. It situates the analysis of the accumulated empirical information firmly within

“wider patterns of power and privilege, oppression and victimization, scarcity and plenty” (Code, 2006: 280).

### *Paying attention to embodiment*

A third distinctive feature of feminist empirical work is that it takes seriously the body and experienced embodiment as constitutive features of moral life. Feminist ethics’ empirical interest is rooted in the observation that the experiences of women differ in significant ways from the experiences of men. The kinds of experience that can be had, and the sense made of them, will differ, to varying extents, according to whether that person is a woman or a man. In acknowledging that much of this difference is the result of gendered social arrangements, it is important not to lose sight of the fact that a gendered difference in experiences is, directly and indirectly, an embodied one (Alcoff, 2006; Bartky, 1990; Young, 2005). The moral subject has/is a body with different physical characteristics and as a result undergoes different kinds of experience, whether that is directly because of biology (for example, pregnancy as a bodily experience currently restricted to women), or indirectly because of the differential social position that societies offer to those bodies that are labelled as female or male. What makes the feminist attentiveness to embodiment useful to bioethics is that embodied experience becomes available, and taken seriously, as material for normative work.

Although standpoint epistemologies are primarily concerned with the epistemic effects of a particular *social* positioning, feminist theory retains the awareness that a gendered social positioning comes about as a result of embodiment. I have a social identity as a woman because I have a body that is phenotypically female. This isn’t always the case; situated knowledge can also result from class, religion, and other categories which may be embodied in complex and subtle ways but which are not primarily to do with bodily features. But in many other instances of marginality, including gender, observable ethnicity, or disability, there is a direct link between the material presence of the body and the kind of situated knowledge that the body can have.

Taking the embodied nature of experience into account makes a further epistemological point. Feminist ethics argues that the materiality of embodiment places genuine constraints on ethicists’ capacity to ‘put ourselves in another’s shoes’ in the effort to understand those others’ ethical perspectives, however good the empirical data we may have about the lives others inhabit (Mackenzie & Scully, 2007). There is always some residuum about having/being a particular kind of body, and the experiences that come with it, which is not transmissible to another person.

It is worth noting here that feminist bioethics’ engagement with the body as a source of morally relevant difference has itself been found problematic by some feminists, who are concerned that it may essentialise biologically based difference and by doing so it puts at risk the feminist goal of transforming the social identities associated with gendered embodiments. Nevertheless, feminist theory attempts to give an account of the body that does not fall back into arguing that bodies are either solely material, or conversely solely a product of discourse, but retains a sense of the (empirically discoverable) possibilities and impossibilities that result from the particularities of the body.

### *Paying attention to marginal voices*

As we’ve seen from the earlier description of Lisa Eckenwiler’s work, some feminist ethical inquiry draws on empirical material that is not in itself feminist to inform a socially and politically grounded account – in that case, of the global practices of care. However, other feminist ethics involves direct, hands-on empirical work. This may be necessary in areas where, for example, longstanding health or social care practices are being reshaped by the advent of new biotechnological innovations. It is not ‘business as usual’, and there may be no existing empirical material to draw on. This kind of feminist bioethics therefore makes use of a range of social science methods, both qualitative and quantitative, to assemble information that provides as accurate as possible a basis for ethical reflection and normative claims.

Feminist empirical ethics tends to draw on a wider repertoire of sources of knowledge than some more familiar forms of empirical social science (Harding, 2005; Hughes & Cohen, 2010; Letherby, 2011; Ramazanoglu & Holland, 2007). That is, it may not privilege institutionally organized natural and scientific knowledge (though it does make use of it), but also attempts to include in a systematic and rigorous way the personal experiences of individuals. There is a strong tradition within feminism, for example, of drawing on phenomenological or narrative accounts to 'ground' theory in lived experience (and it is worth noting there is an equally strong tradition of feminist debate about the theoretical usefulness of such personalised, subjective accounts).

One example of feminist empirical research into the bioethical experiences of a socially marginalised group is provided by a project that I was involved in, with colleagues from the universities of Newcastle and Durham UK, between 2011 and 2014.<sup>69</sup> The aim of this research was to examine the ways in which lay people who self-identified as religious make ethical evaluations about new reproductive and genetic technologies (NRGTs). The methodology included interviews with members of various Christian and Muslim faith groups who had personal experience of making a decision to use (or not to use) an NRGT to address infertility or a genetic condition. We also held group discussions, or dialogue groups (Banks et al, 2006), with people who had not had any direct experience of NRGTs but were willing to discuss the ethics of their use in the abstract. From those with personal experience we also gathered further information, such as how they had actually gone about making their choices, and the effect it had on their later lives and their faith; whether, in retrospect, they would have done anything differently; and whether they had any suggestions to make about improving the process.

I'm describing this research as a form of feminist empirical bioethics, not because it addressed an issue of particular salience to women (though for many novel reproductive interventions that is clearly the case), but rather because it was a systematic attempt to explore the bioethical perspectives of the 'religious': a category of people who, in the United Kingdom and much of mainland Europe, are socially and epistemically marginalised. The United Kingdom is an increasingly secular country in which faith group membership is often nominal. Most bioethical discourse and public bioethical deliberation in the UK is avowedly secular and politically liberal; the theological or doctrinal opinions that do make their way into public bioethics tend to echo the official positions of particular faith groups on health and life science technologies. There is an obvious but generally unaddressed scarcity of information on how lay members of faith groups interpret their faith's official position, and whether and how they then use that interpretation to form their own ethical stance towards NRGTs in general. In a wider context there is equally little knowledge of how people of faith, confronted with a personal need to consider using treatment for infertility or genetic conditions, then navigate their way through the possibly conflicting imperatives of their personal wishes, the wider ethical consensus of society, and the teaching of their faith group.

Part of this project involved us as researchers identifying the epistemic and ethical resources of the religious groups we were investigating. Throughout, we were also attuned to the various ways in which differences in authority and status – often gendered differences, but also differences tracking along structural hierarchies, and across and between different faith groups – affected such things as people's ability to get hold of adequate information about their faith's opinion on the technology, their personal comfort in the clinical setting, and the ease with which they could raise issues relating to their faith practices, or their capacity to contribute their views as people of faith to public bioethical consultations. For example, our Christian participants were members of the state religion; most (but not all) were white and had been living in the UK for generations. By contrast our Muslim participants, most of whom had grown up in the UK, were members of a minority faith, and their families of origin came from countries such as Iran or Bangladesh. Their social position was therefore very different from that of the Christian participants. Our research suggested, among other things, that many of the participants felt that their faith commitment had indirectly excluded them from NRGT services that are in principle available to all. Indirectly, because they were not actively denied access to these services, but because the values and attitudes that came along with their identity as Christian or Muslim – and

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<sup>69</sup> For more details of this study, see the project website <http://www.ncl.ac.uk/peals/research/project/3979>

that were relevant to their infertility, genetic condition and/or its treatment – were, they felt, routinely neglected by their healthcare services. On the whole, our participants felt that this had less to do with hostility towards their religion or ethnic identity than with their faith commitment being discounted as trivial or irrelevant. This had further impact on their capacity to contribute to public bioethical discourse. Many (but not all) of our interviewees and dialogue group participants said they would hesitate to contribute faith-specific points of view to public consultations or debates.

### **The feminist ethics of empirical bioethics: responsibility, and reflexivity**

In this final section, I want to pick up on one further distinctive feature of feminist approaches to empirical bioethics. Feminist empirical methods benefit from academic feminism's long engagement with the ethical and political responsibilities of doing research (e.g. Finch, 1984; Edwards & Mauthner, 2012; Wilkinson, 1998; Ackerly & True, 2008). Questions about the moral responsibility that the feminist researcher holds towards the individuals and groups she is researching, as well as towards the discipline she serves and the academic institutions with which she is associated, are familiar to feminist researchers, especially those who make use of qualitative methodologies and who are confronted very directly with the often problematic relationship between the investigator and those being investigated through the common qualitative methods of interviews, focus groups or ethnographic observation.

All empirical investigation is an opportunity to acquire better information and correct factual inaccuracies about actual practices, beliefs, rationales and so on. The critical ethos of feminist bioethics means that it directs its attention towards those practices, beliefs and rationales that are traditionally neglected or obscured, arguing that this will guarantee ethical theorising that is not just better factually informed but also more just: empirical accuracy therefore becomes an ethical as well as a methodological necessity. For the individual researcher, feminist ethics places a responsibility on the ethicist to be sensitive to the skewed distribution of epistemic authority within social relations in ways that are both critical (looking at how that authority is distributed in the situations under investigation) and self-critical (reflecting on the epistemic authority possessed by the ethicist, and its consequences).

Both these aspects – of critique and self-critique – are illustrated in the example I want to use here. It has become something of a staple of bioethical teaching and debate: the case of “choosing deaf (or disabled) children” (Mundy, 2002; Scully, 2008). Most nondisabled people, and many disabled people too, share the moral understanding that even minor physical or mental impairment involves some degree of disadvantage and suffering, which any good parent would want to avoid for their child if at all possible. This mostly undisputed consensus on the absolute undesirability of physical variation that is disabling lies behind the fascination of bioethicists and public towards the possibility that some people might wish to select *for* rather than *against* impairments in their children. To most nondisabled people, such a choice is profoundly counterintuitive.

Because of the practical impact of bioethical discourse about impairment on the lives of disabled people, the empirical realities of this widely discussed example demand careful examination. Currently what evidence there is (and the scarcity of reliable information here underlines the more general point that our empirical knowledge of the phenomena about which bioethics is asked to make judgements is often woefully limited) suggests that some disabled people do express a *desire* to have a child with the same impairment as themselves. Most notably and notoriously, this has been the case with some members of the signing Deaf community, many of whom identify themselves as a linguistic minority group rather than as disabled. However, there are few known examples of even Deaf people undertaking active steps towards having a child with a particular impairment, rather than just expressing a preference. The best attested of these, and the one that sparked the first wave of media and bioethical attention in the early years of this century, was that of Candace McCullough and Sharon Duchesneau (Mundy, 2002). These two Deaf women deliberately went in search of a sperm donor with a genetically related hearing impairment in order to increase their chances of having an audilogically deaf child.

Feminist analyses of this case have highlighted two things. One is that the bioethical choices (in this case, selecting the features of a future child) made by people from unfamiliar communities who hold a minority point of view are grounded in the situated knowledge and experiences of their particular contexts. Discounting these perspectives, or neglecting to inquire after them at all, is an epistemic injustice. Most importantly, it remains an injustice irrespective of whether or not these perspectives then stand up to subsequent ethical analysis.<sup>70</sup> The case of ‘choosing deaf [or disabled] children’ has been widely discussed in the media and also in the bioethical literature (among others, see Anstey, 2002; Levy, 2002; Savulescu, 2002 & 2007; Hayri, 2004 & 2010; Johnston, 2005; Scully, 2008 & 2011), but mostly unaccompanied by any data indicating, for example, how common a preference for a disabled child might be among disabled or Deaf people, how often any preference is acted on, or what the reasons for preference might be.

At this point, many philosophical bioethicists would respond that these empirical facts are irrelevant to the making of a philosophical argument. It doesn’t matter whether or not a preference is common, or why it is expressed; what they as ethicists are doing is using the intellectual tools of their discipline to examine the normative case for the preference, and if the *information* they draw on is flawed or patchy, that’s not actually a problem for the making of a well-structured evaluation.

By contrast, feminist ethics holds that an ethicist bears political and moral responsibility to be mindful of the consequences for real people of abstract and abstracted theorising. Whether any one bioethicist intends it or not, a lot of bioethical thinking eventually does percolate out into the public domain and go on to influence public opinion and policy. Theorists may believe themselves doing no more than fearlessly following a philosophical argument to its conclusion. Others, however, might then consider they are entitled, or even obligated, to carry those theoretically derived conclusions through into practice.

From a feminist research perspective, the exploitation of real people’s experience – or at least an empirically etiolated version of it – in the service of making philosophical points is irresponsible and profoundly unethical. I’ve been present at a number of conferences or seminar discussions in which the example of ‘choosing deaf children’ was invoked to illustrate anything from issues in identity politics to the semantics of predicting future regret. Each occasion involved the making of claims about the rationales behind deaf or disabled parents wanting a deaf or disabled child, but without any evidence that these claims bore any relation to the reasons that these parents would, in fact, give. The risk is that unsubstantiated ideas, used for the purpose of making an argument, are the explanations that are then incorporated into the bioethical literature, and that may in time influence the deliberations of advisory and policy bodies.

That this is not just a hypothetical risk is exemplified in the story of the UK’s 2008 revision of the Human Fertilisation and Embryology Act. This revision contained a clause banning licensed fertility clinics from using gametes or embryos that contain serious, known genetic conditions, if alternatives are available (Scully, 2011). Given that the number of cases in which this is known or suspected to happen is so low, and also that the lack of agreement on contested terms like ‘serious’ is widely recognised as a problem, the insertion of this clause was surprising. It certainly was influenced by the media interest in the perceived oddity of ‘choosing deaf babies’, but may also have something to do with the disproportionate interest of philosophical bioethics in the structure of a counterintuitive ethical choice, rather than in the empirically discernible reasons behind that choice. Less surprisingly, the eventual insertion of this restriction in the law generated a strongly hostile response at the time from some members of the Deaf and disability community (Emery et al, 2008).

As bioethicists, having the power to define the terms, to give a particular account of events, and to have one’s arguments and claims taken seriously by those with the authority to make things happen, is a power over the lives and wellbeing of others. This power, feminist ethicists would argue, creates responsibilities. In a paper published in 2008 the philosopher Eva Feder Kittay, who has written extensively on ethics and cognitive disability, proposed four maxims of good practice in ethical theorising (epistemic responsibility and modesty, humility, and accountability), asking theorists to

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<sup>70</sup> For discussion of different forms of epistemic injustice, see Fricker (2007); Hookway (2010); Code (1991); Alcoff (2000).

attend to the ethical and practical consequences of the argumentative procedures and examples they use (Kittay, 2008).

A further area of ethical responsibility has to do with reflexivity about one's own position as researcher. Feminist epistemology takes social, cultural and historical position to be important to the formation of distinct epistemic perspectives that need to be taken into account when others' moral practices and choices are evaluated. But feminist epistemology also recognises that the forms of knowledge taken for granted by moral philosophy and philosophical bioethics are not immune to this epistemic distortion. Feminist bioethical approaches necessarily also involve the critical examination of the positions from which we, as bioethicists, carry out our empirical investigations and reflect normatively, of the empirical methods used, the epistemological and sociological assumptions that the use of them reveals, and so on. The inescapable human reality is that all of us are situated observers whose observations are shaped not only by explicit moral beliefs but by much of what we take for granted experientially, socially, institutionally and culturally. Feminist or any other approaches cannot offer a foolproof way around this, other than the constant and necessary reminder that all thinking is thinking from a particular vantage point. This includes the thinking of the moral philosopher: bioethics, whether empirical or theoretical, necessarily is done from a perspective that is dependent on bioethicists' own personal backgrounds and biographies, and also their disciplinary and professional training, and their institutional roles within national and cultural environments.<sup>71</sup> An uncritical and unself-critical empirical bioethics might try to investigate the ways in which an unfamiliar community, such as the Deaf community, ethically evaluates a novel biotechnology, to examine those choices within the framework of the normative judgments of moral philosophy; a more skeptical and distanced approach is necessary in order to examine the cultural, economic and political conditions that shape bioethicists' own lines of sight. Within feminist standpoint epistemology this form of self-scrutiny contributes to what is called 'strong objectivity' (Harding 1993): one that is not grounded in any attempt at epistemic neutrality, but that reflects on a diversity of situated knowledge in order to form better, although never complete, knowledge.<sup>72</sup>

### **The future of feminist empirical bioethics**

Feminist ethics as a whole, including feminist bioethics, is currently at something of a pivotal point in its life. Some distinctive features of feminist approaches – particularly their use of empirical methods – have been absorbed into the mainstream of bioethics, and are no longer remarked on as feminist (Scully et al, 2010). Other aspects of feminist ethics remain positioned as legitimate alternative perspectives. Acknowledging feminist bioethics as an alternative is not, however, the same as integrating its insights into the mainstream of the field. Although sometimes obscured by the competing imperatives of academic research, feminist bioethics' basic political agenda means that it is still driven by a transformative commitment. While mainstream bioethics may have been able to assimilate feminist bioethics' empirical drive, its specifically political goals – which as we have seen inform its epistemological and methodological stances – remain outside of the mainstream. Nevertheless, feminist bioethicists continue to believe that the distinctive insights provided by these approaches are of essential value to the work of bioethics as a whole.

Bioethicists who have taken the empirical turn believe that normative ethics must still have some tethering in fact, if the values and norms it prescribes are going to have any relevance to real world practices. The well recognised problem here is the relationship between the empirical material, whatever form that takes, and the normative content of ethics. Empirical inquiry as commonly understood deals in natural and social scientific facts, while ethics as commonly understood deal prescriptively in norms and values. Ethical work with a substantial empirical component always risks the charge of being purely descriptive and, because of that, not just losing sight of the normative goal of ethical inquiry but losing the capacity to be normative at all. Pellegrino for example writes that it is

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<sup>71</sup> This has not gone entirely unnoticed by others working in empirical bioethics methodology, albeit not from an explicitly feminist standpoint: see, for example, Ives & Dunn (2010).

<sup>72</sup> This notion of moving towards better, but incomplete, moral knowledge is reflected, to varying degrees in Ives' (2014) 'Reflexive Balancing', Landeweer et al's (2016) *Dialogical Empirical Ethics* (in this volume), and the account of moderate objectivism outlined by Sheehan (2016, this volume).

not possible to “extrapolate from the ‘is’ to the ‘ought’ without destroying normative ethics” (Pellegrino, 1995:162).

The extent to which the division between descriptive facts and normative values is real, and/or sustainable, has been extensively discussed as part of the sociology and philosophy of knowledge, and this is not the place to replay that particular debate.<sup>73</sup> The point I want to make here is that a distinctive version of this concern about empirical inquiry eroding ethics’ normative capability is held by most feminist ethicists, who by definition believe that some forms of attitude and behaviour towards women are wrong and others right. The specific point about women has to be extended as a more general claim. As I said earlier, feminist ethics may be pluralist but it can’t ultimately be relativist. Feminist bioethicists want to be able to set normative boundaries to define morally wrong and morally right behaviours in order to prevent exploitation, abuse, oppression and so on of women (and other marginalities) in the contexts of health and life sciences, and this normative ethical goal holds whatever the empirical data may say about the prevalence of exploitative or oppressive practices, and whether or not they are endorsed by powerful groups in society.

Feminists would argue that neither an empirically informed knowledge of others’ lives, nor the capacity for a more critical approach to the sources of our own and others’ ethical beliefs, requires us to abandon bioethics’ normative function of characterising the morally preferable courses of action in healthcare and life science research. And given the current pace of technological and social change in these domains, it is unlikely that the demand for the normative work of bioethics will fall off in the future. The case in favour of *more* empirical work to inform the normative work of bioethics on unfamiliar biomedical terrain is compelling. Feminist approaches offer ways of doing not just more, but better, empirical inquiry: an ethics that is inclusive of marginalised voices and minority experiences, attentive to the hidden cognitive and social biases (including our own) that can derail supposedly impartial reflection, alert to injustice, and that retains a clear sense of the ethical and political importance of normative capability.

## References

- Ackerly, B. and True, J. (2008) Reflexivity in practice: Power and ethics in feminist research on international relations. *International Studies Review* 10 (4): 693-707
- Alcoff, L. 2010. Epistemic identities. *Episteme* 7: 128-137
- Alcoff, Linda Martin, (2006). *Visible Identities, Race, Gender, and the Self*. New York: Oxford University Press.
- Anstey, K.W. 2002. Are attempts to have hearing impaired children justifiable? *J Med Ethics* 28: 286-88
- Baier, A. 1995. *Moral Prejudices. Essays on Ethics*. Cambridge: Harvard University Press
- Banks S., Scully J.L., Shakespeare T. (2006) Ordinary ethics: lay people’s deliberations on social sex selection. *New Genetics and Society* 25: 289-303
- Bartky S.L. (1990) *Femininity and Domination: Studies in the Phenomenology of Oppression*. London; Taylor and Francis
- Baylis, F. and McLeod, C. *J Med Ethics*. Dec 2007; 33(12): 726–731. The stem cell debate continues: the buying and selling of eggs for research
- Borry, P., Schotsmans, P. and Dierickx, K. (2005) The birth of the empirical turn in bioethics. *Bioethics* 19: 49-71

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<sup>73</sup> See MacMillan (2016) and Sheehan (2016), both in this volume, for detailed discussion of these issues.



- Brown, M. 2013. No ethical bypass of moral status in stem cell research. *Bioethics*
- Carse, A.L. and H.L. Nelson (1996) Rehabilitating care. *Kennedy Institute of Ethics Journal*, 6 (1): 19–35
- Code, 1991, *What Can She Know?*, Ithaca, New York: Cornell University Press.
- Code, L. 2006. *Ecological Knowing: The Politics of Epistemic Location*. Oxford: Oxford University Press
- DeVries, R., Turner, L., Orfali, K., Bosk, C. 2007. *The View from Here: Bioethics and the Social Sciences*. Oxford: Wiley-Blackwell
- Dickenson, D. 2006 *The Lady Vanishes: What's Missing from the Stem Cell Debate*. *Journal of Bioethical Inquiry*: 43-54
- Eckenwiler E. (2013) *Long-term Care, Globalization, and Justice*. Baltimore, MD: Johns Hopkins University Press.
- Edwards, R. and Mauthner, M. 2012. Ethics and feminist research: theory and practice, pp 14-28. In *Ethics in Qualitative Research*, eds Miller, T., Birch, M. Mauthner, M. , Jessop, J. London: Sage
- Finch, J. 1984. "It's great to have someone to talk to." Ethics and politics of interviewing women. In: C Bell and H Roberts (eds) *Social Researching: Politics, Problems, Practice*, pp 70-87, London: Routledge
- Fitzpatrick, P. and Scully, J.L. (2010) Introduction to feminist bioethics. In: Scully, J.L., L. Baldwin-Ragaven, and P. Fitzpatrick (eds.), *Feminist Bioethics: At the Center, on the Margins*, pp 1-9, Baltimore, MD: Johns Hopkins University Press
- Fricker, M. 2007. *Epistemic Injustice: Power and the Ethics of Knowing*. Oxford; Oxford University Press.
- Gilligan, C. (1982) *In a Different Voice: Psychological Theory and Women's Development*. Cambridge, MA: Harvard University Press.
- Harding, S. (1991) *Whose Science? Whose Knowledge?* Ithaca, N.Y.: Cornell University Press
- Harding, S. (1993) Rethinking standpoint epistemology: What is 'strong objectivity'? In *Feminist Epistemologies*, eds. L. Alcoff and E. Potter, pp 49-82. London: Routledge
- Harding, S. and Norburg, K. 2005. New feminist approaches to social science methodologies. An Introduction. *Signs* 30: 2009-2015
- Hartsock, N. (1987) The feminist standpoint: Developing the ground for a specifically feminist historical materialism. In *Feminism and Methodology: Social Science Issues*, ed S. Harding, pp 157-180. Bloomington: Indiana University Press
- Hayri, M. 2004. There is a difference between selecting a deaf embryo and deafening a hearing child. *J Med Ethics* 30: 510-12
- Hayri, M. 2010. The moral contestedness of selecting 'deaf embryos'. In: *Arguing about Disability: Philosophical Perspectives*, pp 154-168
- Hedgecoe, A. M. 2004. Critical bioethics: beyond the social science critique of applied ethics. *Bioethics* 18: 120-140
- Hekman, S. Truth and Method: Feminist Standpoint Theory Revisited. *Signs* 22, No. 2 (Winter, 1997), pp. 341-365
- Hoeyer, K (2006) "Ethics wars": Reflections on the antagonism between bioethicists and social science observers of biomedicine'. *Human Studies*, 29(2): 203-227.

- Holland, S., Lebacqz, K. and Zoloth, J. 2001; *The Human Embryonic Stem Cell Debate: Science, Ethics and Public Policy*. Cambridge: MIT Press
- Holm, S. and Jonas, M. 2004. *Engaging the World: The Use of Empirical Research in Bioethics and the Regulation of Biotechnology*. Amsterdam: IOS Press
- Hookway, C. 2010. Some varieties of epistemic injustice: Reflections on Fricker. *Episteme* 7: 151-163
- Hughes, C. and Cohen, R.L. (2010) Feminists really do count: the complexity of feminist methodologies. *International Journal of Social Research Methodology*, Vol. 13(3), pp. 189-196.
- Ives, J. and Dunn, M. 2010. 'Who's Arguing? A Call for Reflexivity in Bioethics', *Bioethics* 24(5): 256-265.
- Ives J. A method of reflexive balancing in a pragmatic, interdisciplinary and reflexive bioethics. *Bioethics* 2014;28(6):302-312
- Jaggar, A. (1991). "Feminist ethics: Projects, problems, prospects". In C. Card (ed.), *Feminist Ethics*, Lawrence, KS: University Press of Kansas
- Jaggar, A.M. 2000. Ethics naturalized: Feminism's contribution to moral epistemology. *Metaphilosophy* 31: 452-468
- Johnston, T. 2005. In one's own image: ethics and the reproduction of deafness. *Journal of Deaf Studies and Deaf Education* 10: 426-441
- Kittay, E.F. and E.K. Feder (eds.), 2003, *The Subject of Care: Feminist Perspectives on Dependency*, Totowa N.J.: Rowman & Littlefield.
- Kittay, E.F. 2008. Ideal theory and the exclusion of people with severe cognitive disabilities. In: Lindemann, H.N., Verkerk, M. and Walker, M.U. *Naturalized Bioethics: Toward Responsible Knowing and Practice*. Cambridge; Cambridge University Press, pp 218-237
- Kittay, E.F., 1999, *Love's Labor: Essays on Women, Equality, and Dependency*, New York: Routledge.
- Landeweer E, Molewijk B, Widdershoven G (2016) Moral improvement through interactive research: An example of dialogical empirical ethics. **This volume**
- Lanoix, M. (2013) Labor as embodied practice: The lessons of care work. *Hypatia* 28 (1): 85–100.
- Letherby, G. (2003.) *feminist research in theory and practice*. McGraw-Hill
- Levy, N. 2002. Deafness, culture and choice. *J Med Ethics* 28: 284-5
- Lindemann Nelson, H. (2000) Feminist bioethics: Where we've been, where we're going. *Metaphilosophy* 31 (5): 492–508.
- Lindemann, H.N., Verkerk, M. and Walker, M.U. (2008) *Naturalized Bioethics: Toward Responsible Knowing and Practice*. Cambridge; Cambridge University Press
- Mackenzie, C. and N. Stoljar (eds.), 2000, *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self*. New York: Oxford University Press
- Mackenzie, C. and Scully, J.L. ( 2007) Moral imagination, disability and embodiment. *Journal of Applied Philosophy* 24: 335-351
- McMillan J. (2016). Empirical Bioethics and the fact/value distinction. **This volume.**
- McLaughlin, J. 2003. *Feminist Social and Political Theory*. Palgrave Macmillan.
- Mundy, L. (2002) A world of their own. *Washington Post Magazine*, March 31

- Pellegrino, E. 1995. The limitation of empirical research in ethics. *The Journal of Clinical Ethics* 6: 161-162
- Ramazanoglu, C. and Holland, J. 2007. *Feminist Methodology: Challenges and Choices*. London: Sage
- Rehmann-Sutter, C. (2010). 'It is Her Problem, Not Ours': Contributions of Feminist Bioethics to the Mainstream. In Scully, J.L., L. Baldwin-Ragaven, and P. Fitzpatrick (eds.), 2009, *Feminist Bioethics: At the Center, on the Margins*, Baltimore, MD: Johns Hopkins University Press, pp 23-44.
- Savulescu, J. (2007) In defence of procreative beneficence. *Journal of Medical Ethics* 33: 284-288
- Savulescu, J. BMJ. Oct 5, 2002; 325(7367): 771–773. Deaf lesbians, “designer disability,” and the future of medicine
- Scully JL. ‘Choosing disability’, symbolic law, and the media. *Medical Law International* 2011, **11**(3), 197-212
- Scully, J.L., 2008, *Disability Bioethics: Moral Bodies, Moral Difference*, Totowa, N.J.: Rowman & Littlefield.
- Sheehan M. 2016. Metaethics, relativism and empirical bioethics. **This volume.**
- Shildrick, M. 2008. The critical turn in feminist bioethics: the case of heart transplantation. *International Journal of Feminist Approaches to Bioethics* 1: 28-47
- Stanley, Liz & Sue Wise (1993) *Breaking Out Again: Feminist Ontology and Epistemology* London: Routledge.
- Tong, R., 1997, *Feminist Approaches to Bioethics: Theoretical Reflections and Practical Applications*, Boulder, CO: Westview Press.
- Tong, R. (2013a) *Feminist Thought: A More Comprehensive Introduction*. Boulder, CO: Westview Press.
- Tong, R. (2013b) International migrant eldercare workers in Italy, Germany and Sweden: A feminist critique of eldercare policy in the United States. *IJFAB* 6: 41-59
- Tronto, J., 1993, *Moral Boundaries: A Political Argument for an Ethic of Care*, New York: Routledge.
- Turner, L. (2009) ‘Anthropological and sociological critiques of bioethics’, *Bioethical Inquiry*, 6: 83-98
- Twine, R. Constructing critical bioethics by deconstruction culture/nature dualism. *Medicine, Health Care and Philosophy* 8 (3):285-295 (2005)
- Twine, R. 2010. Broadening the feminism in feminist bioethics. In: Lindemann, H.N., Verkerk, M. and Walker, M.U. (2008) *Naturalized Bioethics: Toward Responsible Knowing and Practice*. Cambridge; Cambridge University Press, pp 45-59
- Walker, M.U., 2008, *Moral Understandings: A Feminist Study in Ethics*, New York: Oxford University Press.
- Walker, M.U. 2010. Groningen naturalism in bioethics. In: Lindemann, H.N., Verkerk, M. and Walker, M.U. (2008) *Naturalized Bioethics: Toward Responsible Knowing and Practice*. Cambridge; Cambridge University Press, pp 1-20
- Wylie, A. 2003. Why Standpoint Matters. In: R Figueroa and S Harding (eds), *Science and Other Cultures. Issues in Philosophies of Science and Technology*, 26-48, Oxford and New York: Routledge
- Young, I.M. (2005) *On Female Body Experience: ‘Throwing Like a Girl’ and Other Essays*. Oxford: Oxford University Press
- Zussman, R. 2000. The contributions of sociology to medical ethics. *Hastings Center Report* 30: 7-11

# Lessons from experience: Establishing and running interdisciplinary mixed method Bioethics research

Bobbie Farsides  
Clare Williams

In this chapter, we draw on our experiences of working together since 1999 on a variety of projects funded by bodies including the Wellcome Trust and the ESRC. These projects generally focus on what we have described as 'morally contested' areas of biomedicine. Our work often takes as its starting point the adoption or expansion of an ethically challenging health technology, examples of which include innovative antenatal screening, pre-implantation genetic diagnosis (PGD), and embryo donation for human embryonic stem cell (hESC) research. A further common feature has been the focus on the views of practitioners, clinicians, scientists etc. rather than patients. This is primarily because historically, practitioners have tended to be a neglected and under researched group when contrasted with patients. Whilst research into the views and experiences of those accessing ethically contentious technologies remains important (Franklin, 2013), it is also very important to understand the views and practices of those providing (or choosing not to provide) the services.

A significant feature of our work is an established and enduring cross-disciplinary collaboration between Clare Williams (CW), a medical sociologist and Bobbie Farsides (BF), a healthcare ethicist. Whilst the core collaboration has proven remarkably straight forward, there has been a need to reflect carefully over time on how to build wider collaborations – the skill set needed, the ground rules required to ensure amicable working, and the 'philosophy' that should inform shared practice around issues such as anonymity of participants, data sharing etc. An early project revealed the potential for disagreement within interdisciplinary research teams, and the experience of resolving the situation and then reflecting carefully upon it proved very helpful when establishing the working principles for subsequent projects (Williams et al, 2005).

Since first working together in 1999 we have gone on to collaborate with co-applicants from a variety of disciplines including lawyers, clinicians, embryologists, anthropologists, scientists and surgeons. In every project we aim to provide space for each discipline to contribute to the overall endeavour, but also for individual co-applicants to extend and enhance their personal scholarship through access to high quality data. In what follows we will discuss our methods, focusing particularly on Ethics Discussion Groups (EDGs), which we believe constitute a methodologically innovative and empirically rich example of interdisciplinary methods and research in action.

## **Ethics Discussion Groups – concept and purposes**

EDGs are a method of collecting data from groups of staff, following periods of interviewing, and sometimes observation. They are attended by staff who have previously been interviewed for the project being undertaken. For us, EDGs serve a number of different functions.

First, as a component of a mixed methods approach they provide an opportunity to supplement information collected during interviews. Importantly, they also provide interviewees with a second opportunity to reflect upon the issues and consider their views, in a setting that emphasises their identity as a team member.

Second, EDGs are extremely useful in terms of shedding light on group norms and values, and on work place cultures. In some settings hierarchies are obvious and unshiftable, whilst in others the democratic nature of the group is clear. The way in which the team sees itself sitting within the larger institution is illuminating and, because of our intimate knowledge of more than one centre, we can explore how the centre pitches its culture and norms within its professional networks. Commonly,

participants tell stories of 'how things are done elsewhere' and it is sometimes the case that, unbeknown to participants, we have detailed knowledge of that 'other place'.

Third, EDGs are also excellent at identifying shared and common knowledge, and conversely, they can reveal knowledge that staff assumed was shared, but was not. We are particularly interested in how ideas and Unit policies are shaped, and what makes people think and act in the way they do. For example, one of CWs research interests is the interface between private and professional moral views and how this manifests itself in the clinical setting, and EDGs often illuminate this interface. We are also interested in challenging assumptions of homogeneity in moral outlook within teams, having seen over the years that a well supported team can accommodate a wide range of views and practices relating to their work (Farsides et al, 2004).

To date we have run over 20 EDGs for mixed groups of staff, over 4 different research projects, usually with six to eight staff in each group - so around 150 healthcare staff have participated in these groups. We should emphasise that EDGs are not the same as focus groups as standardly understood and conducted. One feature of the method that makes it distinctive is the work that is undertaken before they are held. EDGs only take place once the research team is successfully embedded within the centre, observations are beginning to inform the project, participants have been interviewed and a preliminary analysis of transcripts has taken place. Another feature that makes EDGs distinctive is the way they are run and the role of the facilitator.

### **Facilitating EDGs**

In our projects the EDGs have all been facilitated by BF, with the social scientist researchers who have previously undertaken interviews with participants formally present as observers but also, importantly, as 'familiar faces' who can welcome participants, make introductions, and generally help create a non-threatening atmosphere whilst participants are arriving. In contrast to focus groups, the approach of these EDGs is more akin to a philosophy seminar where the facilitator intervenes and gently challenges individuals in the group setting, providing counterarguments. BF is an ethicist whose background is in philosophy. She has over twenty years' experience of teaching ethics at undergraduate and graduate level. This experience has proved invaluable in conducting the groups and has led us to question whether it would be possible to proceed without experience of conducting seminar style discussions. We, and in particular BF, are not only interested in recording the accounts that people give of their work; we are looking for consistency, coherence, and the values attached to concepts and choices. We are also interested in comparing what they say within the Group setting against what they said previously when interviewed, and to observe how views begin to develop and shift in discussion with colleagues. We are interested in the link between theory and practice and will match what is said in groups to what has been observed in the clinical setting. In line with the 'philosophy seminar' approach, we might challenge participants to acknowledge and explain any discrepancies noted. Perhaps interestingly, we tend not to label anything ourselves as an ethical issue, but leave that to staff to decide. However, if an issue we have begun to think of as critically important to the project fails to emerge in discussion we will guide participants towards it. Over the years we have come to realise that asking staff to identify 'ethical' issues in relation to their work can lead to a narrowing of both the topics raised and the ensuing discussions, as staff try to identify what they think of as 'ethical' issues. In a number of cases, staff have told us that they do not encounter ethical issues in their work, only to go on to produce a long list of ethical clinical, scientific and policy dilemmas, once we remove the word 'ethics' from the conversation (Brosnan et al, 2013).

The role of the facilitator is key, in that the group needs to feel safe and comfortable in terms of clear house rules, appropriate behaviour etc. At the same time, however, the facilitator will seek to push the group out of its comfort zone without exposing individual members. On numerous occasions the groups have brought people into a room together whose work is intricately connected, but who have never had a discussion before; or in some cases have not even met before. The groups also give established teams an opportunity to observe one another afresh and to move beyond what may have become all-consuming clinical agendas. The non-hierarchical nature of the groups' composition means that (if supported to do so) junior staff can give voice to concerns or present issues in the

company of senior colleagues. However, we are always mindful of the fact that participants have to leave the EDGs and go straight back to what is often very demanding clinical work, where they have to work as a team. One of the important tasks for the facilitator is to ensure that no issues have been raised and not dealt with, and that discussions do not result in staff leaving the room feeling unsettled or negative about their work, their colleagues or their centre. Information leaflets about the EDGs contain advice as to where support or counselling can be obtained if participants feel they might need this. In addition, when facilitating, BF emphasises this information before and after the EDG, as well as providing her own contact details should staff want to discuss anything further.

### **The product of EDGs**

After running an EDG we have at least two sets of data from the same group of people: interviews and EDG participation. In addition, we may well have data from observations. However, the group discussions add a crucial layer of data that is in itself analytical in the sense that participants are conducting analyses (of) themselves, through being provided with the unique opportunity to reflect on both their own and others' views on particular topics. The data is discussed at regular multidisciplinary research team meetings throughout the project. For example, we may discuss a particular transcript; a selection of excerpts from a number of transcripts on a particular theme that a team member is interested in; compare interviews and EDGs in terms of what has been said in these different settings; or compare excerpts of transcripts from participants in different centres. These multidisciplinary team discussions have been extremely illuminating in terms of throwing into relief philosophical, conceptual and disciplinary differences and similarities between team members. The importance of mutual trust between team members cannot be over emphasised. What we aim to identify is a set of issues that often lie below the radar of 'normal' ethical scrutiny. We believe this approach is unique in its ability to provide a sociology of ethics in the making (Williams & Wainwright 2013).

### **Towards successful interdisciplinary working – lessons learned along the way**

The first step towards a successful project on staff views and practices is 'buy in' from centres where the work in question is being conducted. This entails detailed discussions and negotiations up-front, usually before funding has been secured, to ensure that the project is understood and accepted by the relevant people and that recruitment can begin as soon as possible once the project commences. As we tend to work on innovative technologies the number of centres involved is usually limited, so factors such as confidentiality and anonymity are a key issue to be discussed at a very early stage. It has often been necessary to cover a range of centres in different parts of the country, and on a very practical note it is important to know what travel will be necessary when planning and costing a project. It is invaluable to identify a key collaborator in each centre and to include at least one key clinician as a co-applicant on the project. We have also found it productive to return to centres to conduct further studies, and indeed projects have been developed in response to requests from participating centres that specific issues need consideration.

An added value of pre-project collaboration is the clarification of the research question, ensuring that the issues identified are of relevance to participants. The first Wellcome Trust funded project we worked on together was entitled 'Cross Currents in Genetics and Ethics around the Millenium:1999-2001'. However, when we arrived at the selected centres we soon discovered that staff did not want to discuss new ways of screening and testing in an antenatal setting until they had shared their concerns about current protocols, most frequently the routine screening for Down Syndrome. As the publications from the project demonstrate, practitioners had many unresolved issues and the project adapted to meet their needs. This was acceptable to the funders and the project was deemed a great success, but it raised an interesting issue of how far we should go to ensure that our research agenda 'chimed' with our participants.

This is not a simple issue. On the one hand, it is practically important to engage the interest of potential participants and to ensure that they feel their time has been well used. For this reason one needs to craft a project in such a way as to ensure that the research question has resonance for

participating centres. However, the researcher also has a responsibility to raise issues which are invisible to people doing the work, or to introduce issues which are being avoided or dealt with habitually rather than critically. And, although it is important and productive to be on good terms with the participating centres, it is also important to retain a degree of independence and a commitment to report honestly and if needs be, critically, upon what is observed<sup>74</sup>. It should always be born in mind that these centres are often undertaking what is seen as ground-breaking work which would often be the subject of praise and encouragement from potential patients and others. We therefore spend time prior to, and during, the project thinking about the potential impact of findings and how we might best provide on-going and end of project feedback and support to individual centres.

Commitment from participating centres is also crucially important because of the relatively demanding methodology we have developed. Commonly we would conduct individual, semi structured interviews with a high proportion of centre staff covering a range of relevant professionals, and including both junior and senior staff. We would also conduct informal interviews and observations in the workplace, as part of a wider approach which might include observing clinical consultations, laboratory procedures, team meetings etc. The staff we interview and observe are the staff who would then be asked to participate in EDGs, so the time commitment for them and their centre is not insignificant. It is also important that the semi-structured interviews and observations are carried out in a way that retains and emphasises the credibility of the researcher and the research team. In practice this means that the researchers need to understand the work that is being carried out and be cognisant of the practical issues that help to shape the working environment. We do not approach centres and participants without having a good understanding of the technology under study, which is considerably helped by the input of clinical co-applicants and collaborators. However on some occasions it might require more than this - for example, on one project the researcher who conducted the ethnographic observations and interviews also attended and participated in a post-graduate course offered by one of the centres. Without this, we would anticipate a drop off of participants agreeing to participate in the project interviews and EDGs, as they are too busy and too immersed in their own work to have the time to bring a researcher up to speed.

Given the business of the centres we study we have arranged EDGs at varying times in the working day, including 8am and 7pm, to accommodate clinical priorities and to fit with normal patterns of working. As well as ensuring maximum attendance, being invited to fit in to the centres' usual routines affords a sense of legitimacy and endorsement. The fact that staff were willing to attend at these times also indicates the paramount importance of maintaining the on-going credibility of the research team, which includes forming good working relationships based on mutual trust.

Establishing contacts and relationships with centres early on has also proved helpful in securing ethical approval and research governance approval from individual Trusts and institutions. At a very practical level, committees are reassured that recruitment issues have been given due consideration and that the researchers have the trust of participating centres. We have never had any problem with securing ethical approval for our work, despite the sensitive nature of the problems we consider, and attribute this at least in part to our good working relationships with centres and staff. However, on some occasions we have had to adapt our plans slightly to accommodate the requirements of the committees. On one occasion for example, the ethics committee was unhappy that the lead clinician in a centre we were studying was also a co-applicant on our project. They required that the individual concerned should not see raw data and should not be aware of when, where or with whom interviews and EDGs were taking place. We agreed to this limitation with some regret, having previously included centre leads in EDGs with great success.

Appreciating that these centres are not sealed off from the rest of the world, we also interview a range of external stakeholders, who give us a different perspective on the technology we are investigating. Although it would be possible to run follow up EDGs for stakeholders too, our key focus has to date been on the clinical teams offering services and this is where the stakeholder interviews make a key contribution. For example, key disability rights activists provided us with an important contrasting perspective in relation to pre-implantation genetic diagnosis. In projects where we have been

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<sup>74</sup> This may be considered to contrast to the approach outlined by Landeweer et al (2016), in this volume, who explicitly avoid engaging in any external critical appraisal of conclusions arising from, or views expressed during, the group process.

interested in developing specific policy recommendations or where participating staff have requested it, we may formalise this process. One successful example of this was by running a multidisciplinary Ethics and Policy Workshop with 20 invited UK stakeholders (who included, for example, patient activists we had interviewed, representatives of a variety of policy and regulatory bodies, and clinicians and scientists), to consider whether embryo donors should be able to restrict the future use of human embryonic stem cells from their embryos. The Workshop was also attended by all of the multidisciplinary research team and was facilitated by BF, who drew on information gained through project interviews, observations and EDGs, which had been discussed by the research team in relation to its use in the Workshop. Participants cited tensions between pure altruism and a more reciprocal basis for donation; and between basic research (in which genetic material would never form part of another living human being) and treatment applications. Two restriction models were agreed on, to acknowledge the specific ethical issues raised by obtaining informed consent for embryo donation (Ehrich et al, 2011). The fact that these models were debated, agreed and then promoted by leading stakeholders in this area (and participants' names and affiliations appeared on the article setting out the recommendations) gave these models a legitimacy that they may otherwise not have had.

Not all interview participants wish to take part in EDGs and this in itself can prove interesting. For example, in one study hospital chaplains were prepared to speak very openly on a one to one basis but felt unable to do so within a group. It can also be the case that a person assumes that their views are very out of step with those of their colleagues and therefore they do not feel comfortable 'exposing themselves'. In this situation we might encourage (but never put too much pressure on) a participant to join a group in the knowledge (gained from interviews with that participant and others) that their views are not going to cause the impact they assume. Because we know the individual views that will be brought into the room we can to some extent predict how a particular individual will 'fit' and be prepared to support them.

Organising the EDGs is not easy and can be very time consuming. We may have ideas about who we would like to participate in each group, but this may have to be adjusted once we know who is available, and when. Once we know who is going to participate in each EDG, the team goes through the interview transcripts of participants, discussing any pertinent observations and picking out potentially interesting topics to be discussed in an EDG context. We will also have asked interviewees at the end of their interview if they would like to suggest topics that might usefully be discussed in their EDG. So these EDG's are in a sense 'tailor made' for the particular set of participants attending that EDG, and in our experience that is important in terms of making the discussion relevant. On occasion we have spoken to interviewees prior to their participation in a group to ask for permission to include a very specific issue or case they have spoken about which might be traceable back to them. This means that they are prepared for it to be mentioned and if they are not comfortable we will approach the subject in a different way. The team meeting observations in particular have proved particularly useful in terms of identifying how centre policy decisions are arrived at. The knowledge gained by observing these meetings is also very useful in terms of providing key topics for individual staff interviews and for the EDGs. By their very nature, the staff within these centres often have a large say in terms of, for example, which tests they will offer, which patients they will treat and how they will respond to new professional guidance, and team meetings are where these important decisions get taken.

In looking back at the transcripts of both interviews and EDGs one appreciates the role and power of story-telling when professionals relay their experiences and reflect upon their practice. Often, project participants would return to an archetypal case (sometimes clearly real and current, sometimes less reliably so) in order to make or challenge a point, or to express their personal take on a professionally shared experience. Sometimes the theme of story-telling was both unexpected and recurrent, such as the stem cell scientists' wish to return to and reflect upon their early experimental work with animals. Some cases stood as exemplars of particularly challenging ethical issues, such as the woman wanting a termination for a 'trivial' reason, or the couple whose wish for a 'perfect' embryo challenged the embryologists' view of what counts as such. This is further evidence, if needed, of the fact that a rigid ethically focused framework was unnecessary when running the EDGs, in that participants could to some extent set their own 'ethical agendas' within the groups.



## Staff perspectives

What we could not have fully appreciated at the outset of our work back in 1999 is the benefits to staff of participating in EDGs (Alderson et al, 2002). One component of the methodology not yet mentioned is the informal but rigorous evaluation of the research experience. Each EDG participant has a telephone debrief conversation with one of the project researchers, and these conversations have provided useful feedback on the methodology. This is important, as although there is an established literature on participating in research including focus groups, interviews and observations, the EDG experience is unique. Participants noted numerous benefits, including support – for example:

Sometimes there are things that you don't want to admit that you're having a tricky time with. It's reassuring to know that other people are as uncertain as you are...we discussed issues that I normally try to suppress (consultant obstetrician).

I liked the reassurance of hearing that other people worried about the same issues, and how broad and varying the range of good practice could be (junior midwife).

They also appreciated the time to reflect on their work and clarify their thoughts:

It's rare to have the chance to sit and contemplate and seriously discuss issues and hear about other people's thoughts; I don't usually have the time (senior midwife).

They're issues we all deal with all the time, but we don't discuss them, partly because we think we can't. But this provides time to formulate what you think. It was extremely helpful to me personally to order my thoughts. That helps you to be clearer to patients (consultant obstetrician).

A number of participants also used the opportunity to request the involvement of the research team in issues relating to the project but beyond its original brief, taking us into the realm of a form of action research. For example, one paediatrician was very keen to introduce antenatal testing for a gene causing deafness, for families who had previously had a deaf child. Her purpose for introducing this was to enable families whose foetus had the gene to prepare for the birth of another deaf child. However, it became apparent in her individual interview that at no time had she considered that couples might use this information to terminate the pregnancy. At her request, this was one of the issues selected for discussion in her EDG, where she realised that termination might indeed result from the offer of testing. During the evaluation, she requested a further discussion with BF, following which she decided to delay the introduction of the testing until further discussion with her clinical team had taken place. Further examples have involved teams who have taken part in one of our projects requesting that we return and facilitate a group discussion of an on-going issue of concern. And, on one occasion, a community clinician requesting our input to a multi-agency workshop, which arose as a result of a problem being identified during an EDG.

## Concluding comments

Martyn Pickerskill (2013) has identified three ways in which 'sociology in ethics' can be useful. First, sociological research methods such as interviews can be used as part of an ethical analysis, which he describes as 'empirical ethics'. Secondly, he illustrates how sociological frameworks can be used to reframe issues of ethical concern. For example, drawing on interviews, Wainwright et al (2006) used the concept of 'ethical boundary work' to show how hESC scientists constructed some embryos as more 'ethical' than others, and drew lines around which embryos they would and would not work with. Finally, Pickerskill argues that sociological analysis of ethical issues can help illuminate key matters of legal, bioethical, clinical and regulatory consideration.<sup>75</sup> In our projects we have many examples of how sociology in ethics can be of value. However, in this chapter we have focused primarily on the

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<sup>75</sup> See, for example, Scott et al. (2012) on the validity and quality of consent for human embryo donation.

use of sociological methods in our various projects and how the particular methodology we have developed builds upon but also extends standard sociological approaches.

We believe that this approach to interdisciplinary mixed methods research has enabled us to develop a broad, but detailed and contextualised, understanding of the complex social worlds involved in the development and implementation of diverse innovative health technologies. In retrospect, we realise that we were also ahead of the curve in terms of ensuring that our academic work had impact beyond the academic papers we have successfully published across the years. The work is not without its difficulties, but the data produced can be exceptional in so many ways. Undertaking these projects has required a 'leap of faith' on the part of our participants, and we are hugely grateful to all those who were prepared to take such a leap. We hope this chapter illustrates the importance of inter/multidisciplinary research and the benefits that can accrue when people from a variety of disciplines come together around a particular topic, in a spirit of collaboration and intellectual curiosity. Crucially, this requires the ability to be critical about one's own disciplinary background. The benefits of this work include contributions to ethics, clinical and scientific practice, policy, regulation and sociology. The data collected has contributed to books, numerous articles, regulatory and policy developments and many conference papers. However, the benefits are also individual – to work on such projects is stimulating, enjoyable, and fun! Finally, we hope that this chapter will encourage others who might be hesitating to take the plunge into the fascinating and rewarding world of interdisciplinary research and methods.

## References

- Alderson, P., Farsides, B., Williams, C. (2002) Examining ethics in practice: health service professionals' evaluations of in-hospital ethics seminars. *Nursing Ethics*, 9: 508-21.
- Brosnan, C., Cribb, A., Williams, C., Wainwright, S. (2013) Neuroscientists' everyday experiences of ethics: the interplay of regulatory, professional, personal and tangible ethical spheres. *Sociology of Health and Illness*, 35: 1133-48.
- Ehrich, K., Farsides, B., Williams, C., Scott, R. (2011) Constructing an ethical framework for embryo donation to research: is it time for a restricted consent policy? *Human Fertility*, 14: 115-121.
- Farsides, B., Williams, C., Alderson, P. (2004) Aiming towards 'moral equilibrium': health care professionals' views on working within the morally contested field of antenatal screening. *Journal of Medical Ethics*, 30: 505-9.
- Franklin, S. (2013) *Biological Relatives: IVF, stem cells and the future of kinship*. Duke University Press, London.
- Landeweer E, Molewijk B, Widdershoven G (2016) Moral improvement through interactive research: An example of dialogical empirical ethics. **This volume**
- Pickerskill, M. (2013) From 'implications' to 'dimensions': science, medicine and ethics in society. *Health Care Analysis*, 13: 31-42.
- Scott, R., Williams, C., Ehrich, K., Farsides, B. (2012) Donation of 'Spare' Fresh or Frozen Embryos to Research: who decides that an embryo is 'spare' and how can we enhance the quality and protect the validity of consent? *Medical Law Review*, 20: 255-303.
- Williams, C., Wainwright, S. (2013) Bioethics. In Gabe, J. & Monaghan, L. (eds) *Key Concepts in Medical Sociology*, pp 140-43. London, Sage.
- Williams, C., Alderson, P., Farsides, B. (2005) Multidisciplinary Research: culture clash or the best of all worlds? In Hallowell, N., Lawson, J., Gregory, S. (eds) *Reflecting upon Research: the perils, pitfalls and pleasures of doing social science*, pp91-94. Open University Press, London.
- Wainwright, S., Williams, C., Michael, M., Farsides, B., Cribb, A. (2006) Ethical Boundary Work in the Embryonic Stem Cell Laboratory. *Sociology of Health and Illness*, 28: 732-48.

# Publishing research in empirical ethics: Quality, disciplines and expertise

Lucy Frith  
Heather Draper

This chapter looks at some of the challenges for reporting and publishing results in empirical ethics, an emerging methodological approach to ethics research. Many of these challenges have their origins in how empirical ethics is defined and where it sits in relation to other disciplines. Accordingly, we consider the relationship between bioethics and empirical ethics, situating these discussions within the debates over whether bioethics is a discipline and the implications this has for the quality of scholarship and the publishing of results.<sup>76</sup> We explore the construction of academic disciplines in general and examine questions such as: is bioethics a discipline in its own right? Is it a branch of philosophy? Or is it a combination of several disciplines that collaborate to answer certain questions? Following from this, we will consider what counts as expertise in bioethics, as this has a bearing on what bioethicists are seen as contributing when they undertake research in empirical ethics. These insights will then be applied to how empirical ethics should be reported. We will conclude that as empirical ethics grows, general quality and reporting standards will emerge and these will gain more general acceptance as empirical ethics becomes more established.

## What is an academic discipline?

The word 'discipline' is commonly used to delineate a pre-ordained category of academic enterprise, almost like a Platonic form; an ideal type. For an area of inquiry to be seen as lying within a specific discipline it has to follow certain rules and procedures, draw on particular theories, and publish and disseminate in appropriate journals and forums.

Disciplinary conventions can be used as a way to draw boundaries between acceptable and unacceptable scholarship. These conventions can be used both formally, in academic journals or conference presentation requirements, or informally over coffee when discussing someone's work or job candidates; 'she is not a proper philosopher' or 'that is not proper sociology'. These 'not proper' comments are pejorative value judgments and such criticisms are often levied at bioethicists. As Lewens observes, it is often said that the problem with bioethics is, 'that most bioethicists have a limited grip on 'serious philosophy'' (2004:121) and therefore are not proper philosophers.

The increasing importance in the UK of disciplinary boundaries is due partly to the advent of the research assessment exercises (RAEs), which have been organised around subject discipline panels that assess research in a particular domain.<sup>77</sup> The increasing importance of disciplinary boundaries with their own definitions of what counts as 'appropriate', 'good quality' and 'meaningful' research, operates alongside a contrary force: the drive for inter-disciplinarity, defined as, 'any form of dialogue or interaction between two or more disciplines' (Moran, 2001). Inter-disciplinarity aims to break down artificial boundaries between subjects and is seen as a way of addressing the grand challenges facing humanity, such as climate change and food scarcity, something that funders, and hence Universities, are keen to encourage. For example, the Research Councils UK states:

The Research Councils already support a great deal of inter-disciplinary research, which benefits from drawing together insights and approaches from a number of established research disciplines...RCUK wishes to support an enhanced culture of interdisciplinary

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<sup>76</sup> Empirical ethics is a particular methodological approach and as such is applicable to other areas of applied ethics such as business ethics.

<sup>77</sup> In the UK, RAEs are used to rank Universities and rank is used to make inferences about the quality of the research produced by different institutions and research clusters within institutions. There is sometimes a mismatch between what the different subject panels set out in their guidance on eligibility and markers of quality, and how institutions interpret this guidance. Institutions have tended to be conservative and to stick within mainstream examples of research in any particular discipline. As a consequence, bioethics is seen not have a natural fit in any of the subject panels (Kong et al, 2011).

and multidisciplinary research in the UK and to ensuring that its peer review and funding infrastructure is supportive of such work. (RCUK, 2014)

Inter-disciplinary work comes with costs: there is uncertainty over where to publish the results, difficulties with assessing quality, and outputs do not fit into any of the standard assessment frameworks. All this can limit understanding and appreciation of inter-disciplinary research. As Marilyn Strathern commented: “one knows one is in an interdisciplinary context if there is resistance to what one is doing” (2005:130). All these issues are relevant to empirical ethics and we will consider them below.

If inter-disciplinarity means crossing disciplinary boundaries, this raises the question of what these boundaries are. There are many accounts of what a discipline is, and there is not space in this chapter to go into this in detail. As Krishan (2009) states, there are different approaches to conceptualising academic disciplines that include sociological, anthropological, philosophical, historical and management/organisational perspectives. In an attempt to determine what the essence of a discipline is, Krishan sets out the following elements:

- “disciplines have a particular object of research (e.g. law, society, politics), though the object of research may be shared with another discipline;
- disciplines have a body of accumulated specialist knowledge referring to their object of research, which is specific to them and not generally shared with another discipline;
- disciplines have theories and concepts that can organise the accumulated specialist knowledge effectively;
- disciplines use specific terminologies or a specific technical language adjusted to their research object;
- disciplines have developed specific research methods according to their specific research requirements;
- disciplines must have some institutional manifestation in the form of subjects taught at universities or colleges, respective academic departments and professional associations connected to it.” (Krishnan, 2009:10)

The more of these characteristics a subject can claim, the more likely it is to be seen as an academic discipline capable of producing a body of scholarship (Krishnan, 2009). The last element is crucial as,

only through institutionalisation are disciplines able to reproduce themselves....A new discipline is therefore usually founded by way of creating a professorial chair devoted to it at an established university.’ (Krishnan, 2009:11)

Pierce notes:

Although most studies fail to define the term [discipline] explicitly, they typically assume that boundaries of disciplines closely follows those of academic departments...[their] importance in creating and maintaining disciplinary communities makes the academic department the building block from which disciplines are created. (1991:22-23)

The history of the discipline of philosophy can be traced using this institutionalised focus, starting with the founding of a new chair and charting its subsequent development. One of the first ‘philosophy’ chairs was the Knightbridge Professor founded in 1683 at the University of Cambridge, originally called the Chair of Moral Theology or Casuistical Divinity, and often known as the Professor of Casuistry. In Cambridge before the early-19<sup>th</sup> century the only degree – or tripos – that could be studied was mathematics. A classics tripos was introduced in 1822 but was only available to graduates of the mathematics tripos. Philosophy began as part of an area of study called moral sciences (which included moral philosophy, political economy, modern history, general jurisprudence and the laws of England), which was introduced in 1848 and became a tripos in 1851 and honours in 1861. Around the middle of the 19<sup>th</sup> century subjects began to become more defined and specialised.

Law created its own tripos in 1858 with history and these split in 1870. Economics became a separate degree subject in 1903. What was left of the original moral sciences tripos continued till it was renamed 'philosophy' in 1970. In 1881 the Chair of Logic, Mental & Moral Philosophy, and Political Economy at University College Liverpool was founded and became the Chair of Philosophy in 1891. Hence, philosophy in its current institutional form has only existed for slightly over 100 years. In the nineteenth century psychology and philosophy were not seen as separate disciplines. Theorists who are now seen as philosophers, Hume, Hobbes and Locke, produced elaborated accounts of psychology; for Mill, logic was part, or a branch, of psychology; William James is seen both as an ancestor of psychologists and philosophers. The journal *Mind*, when it was founded in 1878, published articles that nowadays would be considered to be psychology. What we now know as economics had a similar relationship with philosophy. Adam Smith is an important theorist for both modern disciplines and economics was part of the original moral science tripos in Cambridge until 1903 when, as a discipline, it moved away from moral aspects (Alvery, 1999) and became a discipline in its own right. Now, University departments are moving away from 'traditional' (20<sup>th</sup> century) disciplinary boundaries to being organised around areas of study to reflect the aspiration for a greater inter-disciplinary focus (such as departments of health and well-being).

Societal concerns, funding, teaching requirements, location of academics (i.e. philosophers in medical schools) all combine to change the profile of academic disciplines. Disciplines can be seen as specific practices, with rules that determine which kind of statements are accepted as true or false within that particular discourse (Lyotard, 1984). Academic disciplines are socially contingent bodies with specific discursive strategies to address an area of shared concern. They are essentially 'communities of practice,' defined as: 'groups of people who share a concern or a passion for something they do and learn how to do it better as they interact regularly' (Wenger, 2006). Disciplines are not fixed or discrete entities, but continually change and evolve. It is against this historical background that we can begin to answer the question of whether bioethics is an academic discipline in its own right, recognising that bioethics, and now empirical ethics, are part of the changing evolution of academic subjects and disciplines.

### Bioethics – discipline or not?

Bioethics arose out of philosophy. 'Bioethics' is characterised as the "investigation of ethical issues arising in the life sciences...by applying the principles of moral philosophy to these issues" (Bennett & Cribb, 2003:10). At the 'birth of bioethics' philosophy and theology shaped the discipline with their methods and structures of abstract universal foundationalist theorising (Jonsen, 1998). Although bioethics is *informed* by other disciplines – its central methodology is philosophical. As Green observes,

(w)hile ethics and moral philosophy may sometimes represent a relatively small part of the actual work of bioethics ... the methods of ethics and philosophy remain indispensable to this domain of enquiry (1990:182).

Arguably bioethics has changed and evolved since its beginnings in the middle of the 20<sup>th</sup> Century. It now encompasses a more divergent view of ethics, drawing on a wider theoretical cannon (such as care ethics, feminist perspectives, post-modernism) and using different approaches to solve moral problems (such as empirical methodologies) (Herrera, 2008). Under our definition we would argue that bioethics is a discipline in its own right, it is a community of scholars, with its own journals, conferences, networks and ways of approaching and debating moral problems and issues in the area of the life sciences. This community includes others from disciplines such as medical law, medicine and sociology who contribute to this specific community of practice.<sup>78</sup>

Considering the development of empirical ethics through the lens of our conception of academic disciplines, we argue it is another step in the evolution of bioethics that should not be ruled out on predetermined theoretical commitments to 'pure' philosophical method. There is not space in this chapter to revisit why bioethics in its philosophical form might use empirical data, how this relates to moral theory and the is/ought debate, nor why we need a particular discipline or sub-set of bioethics called 'empirical ethics'. These questions have been debated extensively elsewhere<sup>79</sup> (Molewijk &

<sup>78</sup> It is more institutionalised in the US, with departments of bioethics, but there are centres for bioethics in the UK.

<sup>79</sup> Including in this volume.

Frith, 2009), but for our purposes we will take empirical ethics to be one of the *methods of inquiry* used by bioethicists to approach and explore moral issues.

Empirical ethics moves away from what might be seen as the safe and established shores of philosophical method. As we have noted, bioethicists are often accused of not being proper philosophers, but with the advent of empirical ethics we now might be subject to the charge of not being proper sociologists as well. To address, what ultimately comes down to, the issue of who is given the privilege of having their research recognised and valued within the academic community of bioethics and outside, we will first consider the debate over what constitutes 'expertise', first in relation to bioethics, and then to how one qualifies as an expert in empirical ethics.

## Expertise

There has been extensive debate about what constitutes moral expertise and how this relates to the role bioethicists occupy on public bodies or when offering ethical advice (for example in a clinical setting).<sup>80</sup> There is a close link between how we define moral expertise and how moral judgments are justified (Gesang, 2010), but moral expertise can also focus on the process of decision-making rather than an ability to make 'correct' moral judgments. When considering whether bioethicists in their role *qua* bioethicists are experts, it is important to define exactly which role of the bioethicist we are talking about. As Archard notes, with reference to 'ethics experts' on public bodies, "[t]he fact that moral philosophers sit on the bodies in question is not tantamount to the *exercise* of the moral expertise" (2011:119-120). The nature of committees, he argues, is such that no one person is making the decision and usually such bodies make general policies recommendations rather than dictating specific actions. Thus, bioethicists on committees cannot be said to be making moral decisions in the way one might in one's personal life. Nor can medical ethics consultants, certainly in the UK, who might be called in to advise on more pressing decisions, be said to be making decisions; their role is advisory and it is the health care professionals concerned who are the ones actually making the decision. Driver's distinction between 'three distinct forms of moral expertise' is useful here:

the expert judger, who does a better job of arriving at true moral judgments, the expert practitioner, who acts morally well more than others, and the expert in moral analysis who has greater than normal insight into the nature of morality (in some respect). (2013:280)

The final definition seems best to capture the moral expertise of bioethicists; they are experts in moral analysis, which enables them to identify moral issues, moral distinctions, non-sequiturs in moral reasoning, and to locate issues within the context of ethical theory.

For Caplan, those trained in ethics have a set of traditions and theories that enable them to deliberate about and judge moral issues:

A fully developed applied ethic would afford the moral philosopher an opportunity to examine the delicate interplay that occurs among fact, social roles and prescriptive principles in reaching moral decisions. (1982:16)

An ethicist has expertise in both normative theories and concepts and a good understanding of the area they are considering. An important aspect of this role is not just accepting the moral problems as presented by, say, doctors, because:

[a] knowledge of ethical theories, traditions and concepts allows the moral philosopher to see the normative aspects of ordinary events in ways that those more directly involved do not and sometimes will not. (Caplan, 1982:14)

Thus, the ethicist has the role of identifying and defining moral problems rather than simply offering solutions. Using ethical theory can highlight and clarify the areas of disagreement and discern underlying ethical problems and tensions. Theories and principles can be a tool for elucidating and analysing the data (Frith, 2012), just as, for example, sociologists use theories of social interaction to approach their data (Maxwell, 1996).

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<sup>80</sup> See also Edwards & Deans (2016), in this volume.

This view, as Singer notes, takes expertise as a *skill*:

... the moral philosopher does have some important advantages over the ordinary man. First his general training...should make him more than ordinarily competent in argument and in the detection of invalid inferences...his specific experience in moral philosophy gives him an understanding of moral concepts and of the logic of moral argument. The possibility of serious confusion arising if one engages in moral argument without a clear understanding of the concepts employed has been sufficiently emphasised...Clarity is not an end in itself, but is an aid to sound argument. Finally there is the simple fact that the moral philosopher can, if he wants, think full-time about moral issues, whilst most other people have some occupation to pursue which interferes with such reflection. (1972:117)

Lillehammer talks about the advantage of being able to devote sufficient time to this type of deliberation:

the role of bioethicists is vindicated by their possession of a critical and systematic mastery of ethical concepts and positions, of the presuppositions of such positions, and the relations and distinctions between them. It is in the application of this knowledge that philosophical expertise comes into its own right by encouraging a more informed level of debate in bioethics. It is not that bioethicists offer expertise that scientists, doctors, or politicians are in principle barred from acquiring on their own. It is rather that the division of intellectual labour provides the benefit of input from persons devoted to the systematic study of the theoretical complexities embodied in ethical concepts applied in practical bioethical debate. (2004:133)

At the heart of these skills-based accounts is that a good bioethicist is not more likely to make better moral judgments, but they are likely to help others to make better moral judgments by aiding the process of decision-making.

This suggests a process account that could be constructed along the lines of the importance of employing procedural justice, akin to Daniels' (2008) accountability for reasonableness approach. This approach privileges process because there is unlikely to be agreement on substantive decisions. Richard Ashcroft (2008) has expressed concerns that process accounts abrogate bioethicists' responsibilities and ultimately makes them redundant. Instead, he argues, bioethicists should be producing and defending substantive moral arguments, and this is the unique contribution of the bioethicist in policy forums. There are two rejoinders to this view. First, in a committee neither the bioethicist, nor any other individual, is asked to make a moral decision. Rather, it is the job of the committee to come to some collective decision. Second, as Frith has argued elsewhere (2009), good process can lead to good substantive moral decisions – the process and end are not separate entities.

In conclusions what determines a bioethicist's skill and usefulness is essentially the skill of argumentation, the ability to pick out key moral issues and determine ways of thinking about moral problems that might not be immediately available to the non-bioethicist. This raises the question of how does empirical ethics fit into bioethics expertise as we have conceptualised it?

### **Empirical ethics and expertise**

The answer to this question depends on one's conception of empirical ethics and, as argued above, *our* conception of empirical ethics keeps at its heart a broad conception of philosophical method and corresponding skills. There are different forms of empirical ethics and different ways in which the relationship between empirical data and ethical theory can be conceptualised (as demonstrated in this volume). Does empirical data leave ethical theory unaltered? Or does empirical data have some influence on the actual content and structure of ethical theory itself? To consider the different conceptions of empirical ethics and what contribution bioethicists might make to empirical work, we want briefly to give an overview of the empirical work conducted in bioethics to illuminate different

forms of empirical ethics. Draper and Ives (2007) categorise<sup>81</sup> different ways sociological research has been employed in ethical reasoning, and thereby provide an example of how two different disciplines might come together under the 'empirical ethics umbrella.' The three broad categories are: i) sociology of bioethics; ii) sociology for bioethics; and iii) sociology in bioethics.<sup>82</sup> It is possible that some studies could fall into more than one category – the categories are not mutually exclusive.

### *Sociology of bioethics*

This incorporates two aspects: (1) seeing bioethics and bioethicists as objects of study and (2) examining the social context of bioethical issues or problems. Ethical issues may be studied by the methods of social science. The papers in de Vries *et al.*'s edition of *Sociology of Health & Illness* (2006), for example, are largely an attempt to put bioethical issues (such as the ethics of research and social policy) into a social context.<sup>83</sup> A sociology of bioethics can engage with ethical theory to varying degrees. Bosk's (1992) study of genetic counselling in a paediatric hospital, for example, although looking at an area of great ethical concern, does not explicitly employ or consider ethical theory in its analysis. Other studies and authors critically engage with ethical theory and use their studies to demonstrate what they see as failings in the traditional bioethics. Anspach (1993), for example, in her study of decision-making in an intensive care nursery, explicitly engages with the bioethical debate over life and death decisions in intensive care. Alderson (1990) used her empirical findings to advance a form of the 'social science critique' of bioethics.

### *Sociology for bioethics*

This type uses empirical research to produce data for bioethics. In practice, says Weisz, social scientists, "can provide ethicists with data, ranging from descriptions of the historical origins of current ethical debates to information about how people in different cultures and at different social levels actually behave in ethically problematic situations" (1990:5). Empirical research could be used to identify moral issues that need to be studied. Baruch Brody argues for this sort of role for empirical research in bioethics:

'It can identify issues that actually arise and processes actually used for dealing with them, thereby suggesting where normative analysis is most needed.' (1993:218)

The models of sociology of and for bioethics largely keep the disciplinary boundaries between ethics and sociology separate. There is ethical theory on the one hand and there is sociologically gathered evidence on the other.

### *Sociology in bioethics*

This attempts to break down the boundaries between empirical evidence and ethical theory. It uses empirical data to directly alter and shape ethical theory:

For example, one might wish to modify the theory of patient autonomy towards the social practice of surgical decision-making in elderly men on the basis of empirical data. (Stigglebout *et al.*, 2004:269)

Thus, "bioethical theorising...is not removed from lived experience – it is based upon it." (Draper & Ives, 2007:325)

There are many forms of empirical ethics, each with a different emphasis depending on the disciplinary background and concerns of the research team. There is no single right way of doing empirical ethics; it depends on what the aims of the study are (Ives & Draper, 2009). It is now accepted, in the general research community, that neither qualitative nor quantitative methods are

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<sup>81</sup> There are obvious limitations with constructing any typology of this nature. The intention is to broadly group approaches that share certain characteristics for clarification purposes.

<sup>82</sup> These categories are similar to those often used in medical sociology (White, 2002).

<sup>83</sup> See also Haimes' work on genetic databases, discussed in Haimes & Williams (2007).



intrinsically 'better' than the other.<sup>84</sup> Rather, which paradigm you draw on depends on the research question and the key aspects of the world that one wants to investigate. We consider the same is true of empirical ethics.

### **Role of the bioethicist in empirical ethics**

To return to the question of what the philosophically orientated bioethicists can contribute to empirical ethics work, we take our favoured definition of empirical ethics as one that incorporates some form of normative, and hence philosophical, method, and integrates this with empirical data; a form of sociology *in* ethics. It could be argued that ethicists, trained in philosophy, are not the best people to carry out the research from which these data are derived. Levitt (2004), for example, argues that bioethics and sociology should remain complementary rather than seeking to become more integrated. Appiah, who despite being very sympathetic to the use of empirical findings in the discussion of moral deliberation says: 'Philosophy should be open to what it can learn from experiments; it doesn't need to set up its own laboratories.' (2008:3)

There are two reasons we argue that bioethicists should be involved in the actual conduct of empirical studies and thereby involved in forming a distinctive type of empirical ethics inquiry based on bioethical expertise rather than just leaving it to sociologists. First, a study designed by an ethicist and therefore driven by predominately 'ethical' concerns will have a different emphasis and focus from those conducted by sociologists. This is not the only way to approach ethical issues or areas, but there is room for studies of this type alongside more conventionally conceived sociological ones. Second, ethicists might (and this is a more controversial claim) be better able to design studies that produce the kind of data that are of use in conducting an ethical analysis. For example, if interview data is collected by an ethicist there will be a difference in how the conversations are focussed, the prompts used and the ideas explored that will focus more on the normative aspects of the encounter.<sup>85</sup> Even if the claim that ethicists might be better at collecting their own data for their own purposes is disputed, our central claim is that there is room for a distinctive type of empirical ethics study: a study that uses ethical theory and principles in the collection and analysis of the data and seeks to say something about the theories and principles themselves as well as the phenomena under study (Frith, 2012). Hence, it is valuable for ethicists to carry out their own empirical studies, and in doing so they can make a distinctive contribution to the literature and create a 'community of practice' that integrates empirical evidence and moral theorising.

### **Quality and reporting**

We have described a particular form of empirical ethics that integrates moral theorising and empirical research and therefore creates, arguably, a 'new' form of academic inquiry. There have, however, been concerns expressed about the quality of this kind of empirical ethics, claiming it is bad philosophy, bad sociology or a combination of both. In this section we will address these issues as they relate to our conception of empirical ethics, sociology *in* ethics. Other forms of empirical ethics that do not integrate the normative and the empirical may not face such reporting challenges as they are able to report along more conventional disciplinary lines.

The debate over the quality of empirical ethics mirrors the one that has taken place over quality in qualitative research. This debate is particularly relevant here, as empirical ethics has drawn heavily on the insights provided from qualitative research. Like empirical ethics, qualitative research has had to spend a considerable amount of time justifying why it is a suitable alternative approach to quantitative techniques (Murphy et al, 1998). Hurst (2010) argues that empirical ethics has focussed for too long on more meta-ethical issues such as how to bridge or accommodate the fact/value distinction. This has 'clouded' the more practical methodological concerns by having the debate at a level of abstraction that is removed from quality concerns over the actual presentation and analysis of data. The concern with meta-ethical issues is understandable and appropriate for a new discipline/area of inquiry/or community of practice where the rationale and foundations of why we are doing something need to be articulated and defended. However, it is now appropriate to move on to

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<sup>84</sup> Although the recent decision of the BMJ not to publish qualitative research may suggest the value of such research is still being questioned (Greenhalgh, 2016).

<sup>85</sup> Farsides and William's work is a good example of this, and they elaborate on this approach in this volume.

think about how research in this area is designed, conducted and reported and how we distinguish 'good' research in this area from 'bad' or 'less good'.<sup>86</sup>

Hurst argues that,

'[i]deally, empirical research in bioethics should meet standards for empirical and normative validity similar to those used in the source disciplines for these methods, engaging when needed with colleagues within these disciplines, and articulate empirical and normative aspects explicitly and appropriately.' (2010:444)

This is one approach, but as empirical ethics integrates elements from these source disciplines (for example, but not exclusively, sociology and philosophy<sup>87</sup>) there needs to be some account of how the two are integrated in a robust way. The 'Empirical Ethics Working Group' from Germany (Mertz et al, 2014; Salloch et al, 2012) see this element as important; and Salloch et al (2012) argue that good quality empirical ethics research has to be based on an account of the conceptual relationship between the normative and empirical. It could, therefore, be argued that good quality research in empirical ethics has to incorporate rigour in both components of empirical ethics (i.e. bioethics and sociology) and then explain how the two aspects are integrated or inform each other.<sup>88</sup> This seems a sensible requirement.

## Reporting empirical ethics

Questions of quality are closely connected to issues of how to report results and publish empirical ethics research. Often, what may appear to be flaw in a study is a consequence of poor reporting and, similarly, good, polished reporting of a study can hide a multitude of sins. Reporting can be a particular challenge for interdisciplinary research, as conventions for disciplines differ. There are a few journals that explicitly welcome<sup>89</sup> or are dedicated to empirical research in bioethics. The *American Journal of Bioethics: Empirical Ethics* journal, for example, recognises that there are different reporting conventions and in its guideline for authors says:

'Many disciplines are welcome; flexibility with respect to methodological approach; structure of manuscript can fit the methodology; less strict about word/page limits; focus on integrity of methods' (Miller, 2013).

The main issue for reporting empirical ethics is that this type of research does not have its own established reporting norms and has to fit in with either the norms of bioethics and philosophical style papers or the requirements for empirical papers (such as those that require papers to be structured with background, methods, results and discussion). Adopting either approach will involve compromises in the reporting of the data.

As it was argued above, if empirical ethics papers are expected to give an account of the empirical data, the ethical reasoning and how the two are integrated, this can present difficulties both in the format required by some journals and in the restrictions on the length of journal articles. This presents a challenge for researchers to navigate and makes it hard to include all the key elements in one paper. The tight word limits imposed by some journals, for instance, may force authors to choose between elaborating on the method and discussing the distinctly ethical implications of the data reported in detail. Concentrating on the latter may obfuscate reviewers' attempts to consider the quality of the study design, whilst neglecting this aspect in favour of the former may result in other reviewers being unconvinced that the normative conclusions have been properly justified. Word limits in journals, particularly medical journals, are a problem for all healthcare researchers using non-quantitative methods. The increasing use of online supplementary material by journals has meant that space issues could, potentially, be overcome. But even here deciding what is 'supplementary' can be an issue.

<sup>86</sup> See also Singh's (2016) chapter in this volume.

<sup>87</sup> Empirical ethics draws on other disciplines i.e. psychology, but in this chapter philosophy (specifically ethics) and sociology will be used as examples of the disciplinary tension between abstract and empirical theorising.

<sup>88</sup> For examples of an explanation of the method of combining the empirical and the normative see Frith (2012), Ives (2014), Molewijk et al. (2004), as well as the above chapters in section 2 of this volume.

<sup>89</sup> For instance Clinical Ethics based in the UK has a section dedicated to empirical ethics

So, how might these difficulties of reporting everything in one paper be addressed? We might set out two possible responses; but they are a far from ideal, and illustrate the difficulties of having to work within reporting structures designed for other disciplines.

First, the results could be divided up, reporting empirical findings according to qualitative norms in a journal friendly to qualitative methods and the normative dimensions and reflections in bioethics journal, making reference to the findings published elsewhere. What is then lost is the element of integration that justified the choice of methodology for the original study design. And, perhaps worse, appears to lend weight to the 'jack of all trades, master of none' characterisation of empirical ethics researchers (Dunn et al, 2008).

Second, the scope of the findings reported could be curtailed, perhaps even reporting and discussing only a single finding in an attempt to do justice to both reporting norms and simultaneously demonstrate the value of integration. There are several dangers here too. One is that it appears to be making much of little, as the richness of the entire data set is somewhat hidden. Another is that it opens researchers either to the charge of unethical research practices as data is collected that is not reported, or it creates an appearance of salami publication as the process has to be repeated over several papers so that the full richness of the data can emerge. It is far from obvious which of these pragmatic responses is best, and neither represents how an empirical ethics project should ideally be reported.

These disciplinary specific reporting norms are also reflected in the reviewer pool operated by journals. Bioethics journal reviewers might not want or feel able to judge the methods sections of an empirical ethics paper and may be critical of the normative analysis arguing that insufficient attention has been paid to that aspect. Sociology journal reviewers may want more on the methods and be critical of the theoretical underpinnings of the paper, as they are unfamiliar with ethical theory and forms of argument.

As inter-disciplinary research becomes more established, and alongside this empirical ethics, then hopefully journals will be amenable to more varied reporting norms that can encompass different forms of research and provide better forums for this kind of research.<sup>90</sup>

### **Assessing quality**

In practice how might the quality of empirical research be assessed? It is our view that these quality issues will increasingly be addressed as the area grows and a body of good practice builds up. To draw on the debates over quality of qualitative research again, there has been growing consideration of how to assess the quality of qualitative research (see Murphy et al, 1998; Spencer et al, 2003). This has culminated in the formulation of some broad checklists for quality assessment. A similar type of checklist could be produced for empirical ethics and Mertz et al (2014) have begun to develop this for empirical ethics. They formulate what they call a 'road map' with four criteria:

1. Reflection on the relationship between empirical research and normative research questions – this addresses how the two elements are integrated and what theoretical frameworks underpin the study.
2. Relevance – this relates to the relevance of the study both for advancing scientific and ethical understanding and relevance to society ('impact' in UK parlance).
3. Inter-disciplinary research practice – this has some overlap with the first criteria, and is focussed on how different disciplines interact (i.e. how decisions are made on a project with sociologists and philosophers), how data is gathered and analysed and the conclusions reached.
4. Research ethics and scientific ethos – such as informed consent, competing interests, reporting and consequences for the future.

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<sup>90</sup> Arguably more established researchers in this area could channel efforts into attempting to change the reporting cultural and norms of traditional journals – something that may be helped by exploiting the impact advantages of interdisciplinary findings – and by themselves being willing to support newer and specialist journals, not just by taking up seats on editorial boards and committees but also by using them as an outlet for their own papers and thereby contributing to the virtuous cycle that will increase the citation rates for these journals.

There are certain generic criteria that any piece of research can be judged against (relevance of data to answering the research question, robust of data analysis, how well has the research process been documented) although it would not solve debates over quality it could provide a steer in the right direction. These criteria are a useful starting point for debate amongst the empirical ethics community and could be helpful for thinking about what to include in a journal article and how to report results. They provide a set of questions or areas to think about and although they do not provide answers, this is not the job of quality guidelines. Therefore, checklists may only take us so far and there is still room for judgement, and hence disagreement, over what constitutes good quality research in empirical ethics. This is not in itself a bad thing, as all areas and disciplines debate scholarship, critique papers and aim to advance knowledge by improving on what has gone before. This is a sign, in fact, of healthy academic debate.

## Conclusions

In this chapter we have argued that academic disciplines are not static, but ever changing, evolving forms of communities of practice. Bioethics is a relative newcomer on the scene that has grown out of philosophy to become a different kind of community of practice with different ends, goals, publishing forums and norms and, arguably, can be seen as an academic discipline in its own right. Empirical ethics is a further development and, under our formulation, draws on normative analysis and integrates it with empirical research to produce a distinctive analysis of ethical questions or situations. To be an expert in bioethics is to have a set of skills to draw on to help analyse ethical issues; determine and define the key areas of contention. Empirical ethics draws on this kind of expertise and uses this in empirical research that, under our analysis, has a distinctive set of concerns and priorities and makes it a different endeavour (community of practice) from, for example, medical sociology.<sup>91</sup>

It is too early to say whether empirical ethics can be said to be a discipline in its own right or a methodological tool within bio- and applied ethics. As we have framed the concept of 'discipline', there is nothing that would prevent it from becoming a discipline if a sufficiently well developed community of practice grew up and it became institutionally situated. The concerns over quality of this new type of enterprise are not surprising and such concerns are raised about all new forms of inquiry. As empirical ethics develops, quality and reporting issues will be increasingly debated and standards and processes developed and it is unrealistic to expect this to happen overnight. A major hurdle continues, however, to be the RAEs in UK (or local equivalents) used to rank Universities and their different departments. These forms of assessment tend to be conservatively played by academic institutions concerned about league tables. Greater consideration must be given to how to incorporate new forms of research endeavours, such as inter-disciplinary research, in RAEs. These exercises are very important, and shape how Universities focus their endeavours. Therefore, how the quality and utility of empirical ethics is assessed is a crucial issue for this emerging area of academic inquiry.

## References

- Alderson, P. (1990), *Choosing for children: Parents' consent to surgery* Oxford University Press.
- Alvey, J. (1999) A short history of economics as a moral science. *Journal of Markets and Morality*. 2 (1) pp53-73.
- Anspach, R. (1993), *Deciding Who Lives: Fateful Choices in the Intensive-Care Nursery* University of California Press, Berkeley.
- Appiah, K. (2008), *Experiments in Ethics* Harvard University Press, Cambridge, Mass.
- Archard, D. (2011) Why moral philosophers are not and should not be moral experts. *Bioethics*. 29 (3) pp119-127

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<sup>91</sup> See also MacMillan's (2016) chapter in this volume.

- Ashcroft, R. (2008) Fair process and the redundancy of bioethics: a polemic. *Public Health Ethics*, 1 (1) pp3-9.
- Bennett, R. & Cribb, A. (2003), The Relevance of Empirical Research to Bioethics: Reviewing the debate, in *Scratching the Surface of Bioethics*, M. Hayry & T. Takala, eds., Rodopi, Amsterdam, pp. 9-18.
- Bosk, C. (1992), *All God's Mistakes: Genetic Counselling in a pediatric hospital* University of Chicago Press, Chicago.
- Brody, B. (1993) Assessing empirical research in bioethics, *Theoretical Medicine*, vol. 14, pp. 211-219.
- CASP <http://www.caspinternational.org/?o=1001>
- Daniels, N. (2008) *Just Health Care*, Cambridge University Press.
- Draper, H. & Ives, J. (2007) An Empirical Approach to Bioethics: Social Science 'of', 'for' and 'in' bioethics research, *Cognition, Brain & Behavior*, vol. XI, no. 2, pp. 319-330.
- Driver, J (2013) Moral expertise, judgment, practice and analysis. *Social Philosophy and Policy*. 30 (1-2) pp 280-296
- Dunn, M. Gurtin-Broadbent, Z. Wheeler, J, Ives, J. (2008) Jack of all trades, master of none? Challenges facing junior academic researchers in bioethics. *Clinical Ethics* 3(4): 160-163.
- Edwards K, Deans Z. (2016) Empirical Bioethics and the role of the ethicist in policy making: Politics, Authority and Expertise. **This volume**
- Frith, L. (2012) Symbiotic empirical ethics: a practical methodology, *Bioethics*, 26 (4) pp198–206.
- Frith, L. (2009) Process and Consensus - Ethical Decision-Making in the Infertility Clinic: A Qualitative Study, *Journal of Medical Ethics*, 35 (11) pp 662-667.
- Gesang, B (2010) Are moral philosophers moral experts? *Bioethics*, 24;4 153-159.-
- Green (1990) Methods in Bioethics *Journal of Medicine and Philosophy* 15(2): 179-197
- Greenhalgh, T et al. (2016) An open letter to The BMJ editors on qualitative research. *BMJ* 2016;352:i563
- Haimes, E. & Williams, R. (2007) Sociology, Ethics, and the Priority of the Particular: Learning from a case study of genetic deliberations, *The British Journal of Sociology*, vol. 58, no. 3, pp. 457-476.
- Herrera, C. (2008) Is It Time For Bioethics To Go Empirical?, *Bioethics*, vol. 22, no. 3, pp. 137-146.
- Hurst, S. (2010) What empirical turn in bioethics? *Bioethics*, 29 (8) pp439-444.
- Ives, J. 2014. 'A method of reflexive balancing in a pragmatic, interdisciplinary and reflexive bioethics.' *Bioethics* 28, 6, 302-312.
- Ives J, Draper H. Appropriate methodologies for empirical bioethics: it's all relative. *Bioethics* 2009;23:249-258.
- Jonsen, A. (1998), *The birth of bioethics* Oxford University Press, Oxford.
- Kong, W-M et al (2011) Include medical ethics in the research excellence framework, *BMJ* 343:d3968
- Krishnan, A (2011) What are academic disciplines? ESRC NCRM Working Paper series 03/09.
- Levitt, M. (2004) Complementarity rather than integration (a response to integrated empirical ethics), *Medicine, Health Care and Philosophy*, vol. 7, pp. 81-83.

- Lewens, T. (2004) Is something wrong with bioethics? *Studies in History and philosophy of biological and biomedical sciences*,. 35 pp 121–123
- Lillehammer, H (2004) Who needs bioethicists? *Studies in History and philosophy of biological and biomedical sciences*, 35 pp 131-144.
- Lyotard, J-F (1984) *The Postmodern condition*, Manchester University Press.
- McMillan J. (2016). Empirical Bioethics and the fact/value distinction. **This volume.**
- Mertz M. Inthorn J. Renz G. Rothenberger L. Salloch S. Schildman J. Wohlke S. Schicktanz S. 2014. Research across the disciplines: a road map for quality criteria in empirical ethics research. *BMC Medical Ethics*, 15:17.
- Miller, V. (2013) Publishing in empirical bioethics: challenges and opportunities. Online presentation [http://cctst.uc.edu/sites/default/files/files/Miller%2022%20PM%20Publishing%20in%20Bioethics%202\\_19\\_13%20UPDATED\(1\).pdf](http://cctst.uc.edu/sites/default/files/files/Miller%2022%20PM%20Publishing%20in%20Bioethics%202_19_13%20UPDATED(1).pdf)
- Moher et al (2009) Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement, *BMJ* 339:b2535 doi: 10.1136/bmj.b2535
- Molewijk, B & Frith, L. (2009) Empirical Ethics: Who is the Don Quixote? *Bioethics* 23 (4) pp ii-iv.
- Molewijk, B., Stiggelbout, A. M., Otten, W., Dupuis, H. M., & Kievit, J. (2004) Empirical data and moral theory: a plea for integrated empirical ethics, *Medicine, Health Care and Philosophy*, vol. 7, pp. 55-69.
- Murphy, E., Dingwall, R., Greatbatch, D., Parker, S., & Watson, P. (1998) Qualitative Research Methods in Health Technology Assessment: A review of the literature, *Health Technology Assessment*, vol. 2, no. 16.
- Pierce, S.J. (1991). Subject areas, disciplines, and the concept of authority. *Library and Information Science Research*, 13(1), 21-35.
- Research Councils UK (2014) Applications across research council remits, <http://www.rcuk.ac.uk/funding/fundingagreement/> (assessed April 2014)
- Salloch et al. (2012) Empirical research in medical ethics: How conceptual accounts on normative-empirical collaboration may improve research practice. *BMC Medical Ethics*, 13:5.
- Singer, P (1972) Moral Experts. *Analysis* 32(4):115-117)
- Spencer, L. Ritchie, J. Lewis, J and Dillon, L. (2003) 'Quality in Qualitative Evaluation: A framework for assessing research evidence', The Cabinet Office, ISBN: 07715 04465 8.
- Strathern M (2005), 'Anthropology and Interdisciplinarity', *Arts and Humanities in Higher Education* 4:2, p. 130.
- Stiggelbout, A. M., Molewijk, A., Otten, W., Timmermans, D., van Bockel, J., & Kievit, J. (2004) Ideas of patient autonomy in clinical decision making: a study on the development of a scale to assess patients' and physicians' views, *Journal of Medical Ethics*, vol. 30, pp. 268-274.
- Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349-357.
- Weisz, G. (1990), *Social Science Perspectives on medical ethics* Kluwer, Dordrecht.
- Wenger, E. C. (2006) *Communities of Practice: A brief introduction*. <http://wenger-trayner.com/theory/>
- White, K. (2002), *An Introduction to the Sociology of Health and Illness* SAGE, London.